



National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers

October 16–17, 2017

National Institutes of Health

Bethesda, MD

PROGRAM

#DementiaCareSummit



National Institute
on Aging



NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

Goal of the Summit

The goal of this research summit is to identify what we know and what we need to know to accelerate the development, evaluation, translation, implementation, and scaling up of comprehensive care, services, and supports for persons with dementia, families, and other caregivers. The Summit is focused on research that is needed to improve quality of care and outcomes across care settings, including quality of life and the lived experience of persons with dementia and their caregivers.

Cross-Cutting Themes

- Access
- Diversity (gender, race, ethnicity, culture, language, literacy, sexual orientation, socioeconomic status, geographic location, and living situation—alone or with a caregiver)
- Disparities
- Etiologies and disease stages
- Care settings (home, community, assisted living, nursing home, and medical/healthcare settings)
- Employment, training, and workforce issues
- Technology

Anticipated Outcomes

- Research recommendations and priorities to inform federal agencies, foundations, and other private-sector organizations that fund research on dementia care, services, and supports
- Identification of evidence-based programs, strategies, and approaches that can be used now to improve care, services, and supports
- Identification of methodologies to involve individuals with dementia and families in shaping research and participating in studies
- Research milestones to track and guide acceleration and advancement of evidence-informed care and services
- White papers, briefs, and publications summarizing Summit research recommendations and outcomes; possible post-Summit activities to advance policy and practice implications

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TABLE OF CONTENTS

Agenda	2
Participant Biographies	9
Helpful Tips	25
Summit Steering Committee Members	26
Summit Cross-Cutting Chairs	27
Summit Stakeholder Groups	28
Pre-Summit Activities	29

NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

National Institutes of Health
Bethesda, MD
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DAY ONE: OCTOBER 16, 2017

7:00 a.m.–8:00 a.m. **REGISTRATION**

8:00 a.m.–8:30 a.m. **WELCOME AND INTRODUCTORY REMARKS**

Summit Co-Chairs: Laura N. Gitlin, PhD, Johns Hopkins University
Katie Maslow, MSW, The Gerontological Society of America

Sponsor Remarks

Advancing Research Toward Care and Support Solutions

Harry Johns, Alzheimer's Association

The Imperative of Diverse Voices and Collaborative Decision Making

Ian Kremer, JD, LEAD Coalition (Leaders Engaged on Alzheimer's Disease)

Setting Care Goals for 2025

George Vradenburg, UsAgainstAlzheimer's

8:30 a.m.–9:00 a.m. **PLENARY LECTURES: Context for the Summit**

View from the Advisory Council on Alzheimer's Research, Care, and Services

Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine

**Biomedical and Care Research in Dementia: Interdependent
and Complementary**

Maria C. Carrillo, PhD, Alzheimer's Association

9:00 a.m.–10:00 a.m. **PLENARY LECTURES: Demographic Framework**

**Demographics of Dementia and Dementia Caregiving: Key Changes
in the Decades Ahead**

Ken Langa, MD, PhD, University of Michigan

Deconstructing Race, Ethnicity, and Culture for ADRD Research

Jennifer Manly, PhD, Columbia University

Implications of Diversity in Dementia Care, Services, and Supports

Maria Aranda, PhD, MSW, MPA, LCSW, University of Southern California

10:00 a.m.–10:15 a.m. **BREAK**

10:15 a.m.–12:30 p.m. SESSION I: Research on Care Needs and Supportive Approaches for Persons with Dementia

Co-Chairs: Richard H. Fortinsky, PhD, University of Connecticut School of Medicine
Ann Kolanowski, PhD, RN, FGSA, FAAN, Colleges of Nursing and Medicine,
Pennsylvania State University

Speakers

Causality Matters: Preventing and Mitigating Behavioral and Psychological Symptoms of Dementia

Helen Kales, MD, PPA, University of Michigan

Maintaining and Supporting Function in Persons with Dementia

Barbara Resnick, PhD, RN, CRNP, FAAN, FAANP, School of Nursing, University of Maryland

Slowing Cognitive Decline and Supporting Resilience in Patients with Dementia

Davangere P. Devanand, MD, Columbia University Medical Center

Home Is Where the Future Is: BrightFocus Foundation Consensus Panel on Dementia Care

Constantine Lyketsos, MD, MHS, DFAPA, FAPM, FACNP, Johns Hopkins Medicine

Dementia Care in Residential Long-Term Care

Sheryl Zimmerman, PhD, University of North Carolina at Chapel Hill

Technologies for Assessment and Interventions to Improve and Accelerate Dementia Care Research

Jeffrey Kaye, MD, Oregon Health & Science University

Brief Reports and Commentaries

Living Well with Dementia

Melanie (Lonni) Schicker, EdD, MHSA, RN, Persons Living with Dementia Stakeholder Group

Researching Rhythms of Daily Life: The Role of Sleep and Daily Activity in Entraining Circadian Patterns

Nancy A. Hodgson, PhD, RN, FAAN, University of Pennsylvania School of Nursing

Physical and Social Environments for Care and Services: Research Recommendations for the Design of Care Settings

Margaret Calkins, PhD, EDAC, Mayer-Rothschild Foundation

Living Alone with Dementia: Identification, Unmet Needs, and Safety Concerns

Elizabeth Gould, MSW, National Alzheimer's and Dementia Resource Center,
RTI International

Caregiving and Intellectual and Developmental Disabilities and Dementia: Report of the Pre-Summit Workgroup on Caregiving and Intellectual and Developmental Disabilities

Tamar Heller, PhD, University of Illinois at Chicago

Moderated Audience Discussion

12:30 p.m.–1:30 p.m. LUNCH

1:30 p.m.–3:30 p.m.

SESSION II: Research on Supportive Approaches for Family and Other Caregivers

Co-Chairs: Linda Teri, PhD, University of Washington
Lisa Fredman, PhD, Boston University School of Public Health

Speakers

Supporting Family Caregivers Effectively: Lessons Learned from Research

Linda Nichols, PhD, Memphis Veterans Affairs Medical Center

Evolving Knowledge About the Health Effects of Caregiving to Persons with Dementia and Other Conditions

Lisa Fredman, PhD, Boston University School of Public Health

Dyadic Intervention: From Early Stage to End of Life

Carol J. Whitlatch, PhD, Benjamin Rose Institute on Aging

The Use of Technology in the Support of Family Caregivers

Sara Czaja, PhD, University of Miami

Innovating the Next Generation of Dementia and Alzheimer's Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers

Vincent Mor, PhD, Brown University

Brief Reports and Commentaries

Personal Perspectives on Family Caregiving

Sowande Tichawonna, Family Caregiver Stakeholder Group

Dementia Family Caregiving: Recommendations from a Conference to Advance Interventions in Diverse Populations

Oanh Meyer, PhD, MAS, University of California, Davis, School of Medicine

Equity: A Powerful Force in the Future of Sexual and Gender Minority Dementia Caregiving

Karen Fredriksen Goldsen, PhD, University of Washington

Dementia Caregiving in the U.S. Research Recommendations

Gail Gibson Hunt, National Alliance for Caregiving

Family Caregiving's Impact on Women

Mary E. Worstell, MPH, U.S. Department of Health and Human Services, Office of the Assistant Secretary for Health

Moderated Audience Discussion

3:30 p.m.–5:00 p.m.

SESSION III: Involving Persons with Dementia and Caregivers as Members of the Research Team

Co-Chairs: Mark Snowden, MD, MPH, University of Washington
Lee Jennings, MD, MSHS, University of Oklahoma

Speakers

Principles and Practices for Engagement in Research

Lori Frank, PhD, Patient-Centered Outcomes Research Institute (PCORI)

Challenges and Solutions for Involving Persons with Dementia and Dementia Family Caregivers as Members of the Research Team

Jason Karlawish, MD, University of Pennsylvania, Penn Memory Center

European Perspectives and Experience in Involving Persons with Dementia and Dementia Family Caregivers as Members of the Research Team

James Pickett, PhD, Alzheimer's Society (UK)

Brief Reports and Commentaries

Person with Dementia Perspective on Participating as a Member of the Research Team

Teresa Webb, RN, Persons Living with Dementia Stakeholder Group

The Who, What, Why, When, and Where of Care Partners in Research

Sharon Hall, Family Caregiver Stakeholder Group

Moderated Audience Discussion

DAY TWO: OCTOBER 17, 2017

7:00 a.m.–7:55 a.m.

REGISTRATION

7:55 a.m.–8:00 a.m.

INTRODUCTION TO DAY

Summit Co-Chairs: Laura N. Gitlin, PhD, Johns Hopkins University
Katie Maslow, MSW, The Gerontological Society of America

8:00 a.m.–8:30 a.m.

PLENARY SESSION: Nomenclature: Words Matter

The Terminology Issues

Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine

Effect of Stigma on Access to Care and Services

Angela Taylor, Lewy Body Dementia Association

Perspectives of a Family Affected by Dementia

Edward K. Kaplan, PhD, Professor Emeritus, Brandeis University; Persons Living with Dementia Stakeholder Group

Janna Kaplan, MSc, Brandeis University; Family Caregiver Stakeholder Group

8:30 a.m.–9:45 a.m.

SESSION IV: Involving Persons with Dementia as Study Participants

Co-Chairs: Darby Morhardt, PhD, LCSW, Northwestern University
David M. Bass, PhD, Benjamin Rose Institute on Aging

Speakers

Clinical Heterogeneity of Dementia and Impact on Research Participation
Sandra Weintraub, PhD, Northwestern University

Work with Us! We Want to Help: Perspectives of a Person with Dementia on Involvement as a Study Participant
Cynthia Huling Hummel, PhD, BS, MDiv, DMin, Persons Living with Dementia Stakeholder Group

Role of Research in Examining and Understanding the Illness Experience of Individuals with Dementia
Katherine S. Judge, PhD, Cleveland State University

Measuring Disease Impact on People Living with Dementia: PCORI Pre-Summit Summary
Darby Morhardt, PhD, LCSW, Northwestern University, and Lisa Gwyther, MSW, LCSW, Duke University

Moderated Audience Discussion

9:45 a.m.–12:30 p.m.

SESSION V: Research on Models of Care for Persons Living with Dementia and Their Families Across the Disease Trajectory

Co-Chairs: Vincent Mor, PhD, Brown University
David B. Reuben, MD, University of California, Los Angeles

Speakers

Dementia-Specific Models of Care

Components of a Comprehensive Care Model for Dementia
David M. Bass, PhD, Benjamin Rose Institute on Aging

Health System-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities
Zaldy S. Tan, MD, MPH, University of California, Los Angeles

Community-Based Models of Dementia Care: Characteristics, Challenges, and Opportunities
Quincy Miles Samus, PhD, MS, Johns Hopkins School of Medicine

General Models of Care that Include Persons with Dementia

Successful VA Innovations in Geriatric Care
Thomas E. Edes, MD, MS, U.S. Department of Veterans Affairs

Dementia Care Management within the Federal Financial Alignment Demonstration
Debra L. Cherry, PhD, Alzheimer's Greater Los Angeles

Consumer-Directed Care Models
Julie Robison, PhD, University of Connecticut

Service Provider and Payer Reactor Panel

Shari M. Ling, MD, Centers for Medicare and Medicaid Services
Steve Waring, DVM, PhD, Essentia Institute of Rural Health
Nora Super, MPA, National Association of Area Agencies on Aging

Facilitators of Models of Care for Persons Living with Dementia and Their Families

Workforce Size, Composition, Retention, and Competence

Gregg Warshaw, MD, University of North Carolina at Chapel Hill

Quality Measures

Gary Epstein-Lubow, MD, Brown University/Hebrew SeniorLife
Louise Phillips, MD, Persons Living with Dementia Stakeholder Group, with off-site contribution from Brenda Nicholson, MD, Persons Living with Dementia Stakeholder Group

Scaling Up: Research to Promote Diffusion of Successful Models

David B. Reuben, MD, University of California, Los Angeles

Moderated Audience Discussion

12:30 p.m.–1:30 p.m.

LUNCH

1:30 p.m.–4:45 p.m.

SESSION VI: Thinking Outside the Box

Co-Chairs: Christopher Callahan, MD, Indiana University School of Medicine
Alan B. Stevens, PhD, Baylor Scott & White Health

PLENARY LECTURES: Thinking Outside the Box

Moving Forward Faster to Provide Care Together

Christopher Callahan, MD, Indiana University School of Medicine

Retail and the Consumer Lens: An Outside Perspective

Raha Alavi, Nielsen Retail Services

Translation and Implementation of Effective Care, Services, and Supports

Keeping Research Relevant: Moving from RCT to Practice

Linda Teri, PhD, University of Washington

Balancing Treatment Fidelity with Feasibility and Acceptance by End Users

Mary Mittelman, DPH, New York University

Evidence-Based Programs: Mapping Out the Future

Leisa R. Easom, PhD, RN, Rosalynn Carter Institute for Caregiving

Integrating Evidence-Based Dementia Care Programs into Existing Service and Reimbursement Systems

Richard H. Fortinsky, PhD, University of Connecticut School of Medicine

Innovative Research Methods and Outcomes

Research Methods for Dementia Care and Services

Brian Mittman, PhD, Kaiser Permanente; U.S. Department of Veterans Affairs

Stakeholder Perspectives on Research Outcomes that Matter

Sarah Lenz Lock, JD, AARP

New Directions in Measurement for Psychosocial Research on Dementia Care and Services: Report from Two Pre-Summit Meetings

Sam Fazio, PhD, Alzheimer's Association

Understanding What Matters Most to Inform Care and Services Research

Debra Lappin, JD, Faegre Baker Daniels Consulting

New Directions from Different Vantage Points

Moderator

Laura N. Gitlin, PhD, Johns Hopkins University

Discussants

Mark Snowden, MD, MPH, University of Washington

Alan B. Stevens, PhD, Baylor Scott & White Health

Joseph E. Gaugler, PhD, University of Minnesota

Alice Bonner, PhD, RN, FAAN, Massachusetts Executive Office of Elder Affairs

Amy M. Kilbourne, PhD, MPH, Veterans Health Administration

Lisa Onken, PhD, National Institute on Aging

Moderated Audience Discussion

4:45 p.m.–5:00 p.m.

WRAP UP

Speakers

Laura N. Gitlin, PhD, and Katie Maslow, MSW, Summit Co-Chairs

Greg O'Brien, Persons Living with Dementia Stakeholder Group

Venoreen Browne-Boatswain, MEd, Family Caregiver Stakeholder Group

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PARTICIPANT BIOGRAPHIES

Biographies of the Steering Committee Co-Chairs

LAURA N. GITLIN, PHD, is an applied research sociologist, the Isabel Hampton Robb Distinguished Professor, School of Nursing, Johns Hopkins University (JHU), and Director of JHU's Center for Innovative Care in Aging. She is internationally recognized for her intervention research involving social-ecological and person-directed approaches to nonpharmacological dementia care, caregiving, and disability. She joined the Advisory Council on Alzheimer's Research, Care, and Services in 2015 and will be its next Chair. Starting in February 2018, she will be the Distinguished Professor and Dean of the College of Nursing and Health Professions at Drexel University.

KATIE MASLOW, MSW, is a Visiting Scholar at The Gerontological Society of America (GSA). Her work focuses on care-related issues for older people with cognitive impairment and dementia. She was previously a scholar-in-residence at the Institute of Medicine (IOM), National Academies of Science, where she worked on the 2015 IOM report on cognitive aging and directed a series of meetings on advanced dementia. She also conducted policy-related research and reports for the Alzheimer's Association and the U.S. Office of Technology Assessment.

Biographies of the Speakers and Panelists

RAHA ALAVI is Senior Vice President of Nielsen Retail Services. She is accountable for the strategic expansion of Nielsen's relationship with regional retailers throughout the United States. She has more than 20 years of experience leading transformational change at the intersection of analytics, technology, and operational excellence. She spent 14 years in the pharmaceutical industry heading global QA validation and process engineering teams. She then made a shift into the retail industry, where she led strategy, innovation, and analytics teams before joining Nielsen.

MARIA ARANDA, PHD, MSW, MPA, LCSW, is an associate professor at the University of Southern California (USC) Suzanne Dworak-Peck School of Social Work, with a joint appointment at the USC Leonard Davis School of Gerontology. Her research focuses on psychosocial care of adult and late-life psychiatric disorders, and linguistic and cultural adaptations of evidence-based interventions for adults with chronic medical conditions and disabilities. Dr. Aranda has served on several consensus committees sponsored by the National Academies of Sciences, Engineering, and Medicine, focusing on the geriatric workforce in mental health and substance use service sectors, family caregiving to older adults, and financial capacity determination among Social Security beneficiaries.

DAVID M. BASS, PHD, is a Senior Vice President at the Benjamin Rose Institute on Aging (BRIA), a premier, not-for-profit research, service, and advocacy organization based in Cleveland, OH. Dr. Bass joined BRIA in 1984 and has led more than 70 funded research projects on topics such as coping with chronic illness, family caregiving, and models of dementia care. His current research focuses on developing, testing, and implementing evidence-based programs. Results of his investigations have been widely published in scientific and clinical journals and have been used to develop innovative programs and services for older adults and their family members.

ALICE BONNER, PHD, RN, FAAN, is Secretary of the Massachusetts Executive Office of Elder Affairs, an associate professor in the School of Nursing, and a Faculty Associate in the Center for Health Policy at Northeastern University. She was a geriatric nurse practitioner for 28 years. More recently, she has been the Director of the Bureau of Health Care Safety and Quality at the Massachusetts Department of Public Health and Director of the Division of Nursing Homes in the Centers for Medicare and Medicaid Services. Her research interests include quality and safety in healthcare systems and community-based settings, elder abuse, falls prevention, improving dementia care and reducing unnecessary antipsychotic medication use, and improving care transitions.

VENOREEN BROWNE-BOATSWAIN, MED, is a leader with more than 35 years in higher education leadership in student affairs, diversity, and multiculturalism. She is an active community leader, a member of Toastmasters, and a consulting mediator for various companies for more than 20 years. Venoreen is passionate about raising awareness of dementia in communities of color, supporting loved ones of persons with dementia in diverse communities, and informing healthcare practitioners about the experiences of families of color who have received dementia care. She is wife and caregiver for a 10-year person with dementia and has been a member of the Summit Family Caregiver Stakeholder Group.

MARGARET CALKINS, PHD, EDAC, is Executive Director of the Mayer-Rothschild Foundation, the only national philanthropy exclusively committed to person-centered long-term care in the United States. She is nationally recognized as a creative, dynamic leader, educator, and researcher in the field of environments for elders. She has published extensively and has partnered with Pioneer Network, The Green House® Project, and Planetree. She was a founding member of SAGE, the Society for the Advancement of Gerontological Environments, and is on the editorial board for *The Gerontologist*, *Journal of Housing and the Elderly*, *Journal of Clinical Psychology*, and *Health Environments Research & Design Journal*.

CHRISTOPHER CALLAHAN, MD, has served on the faculty at the Indiana University School of Medicine for 27 years. His clinical practice focuses on care for older adults with depression and dementia in the Sandra Eskenazi Center for Brain Care Innovation. He is a research scientist in the Regenstrief Institute, Inc. and the founding Director of the Indiana University Center for Aging Research. He has conducted observational and interventional research to improve the care of older adults with dementia and depression in primary care settings. This work includes clinical trials exploring new models of care seeking to improve the care of vulnerable elders.

MARIA C. CARRILLO, PHD, is the Chief Science Officer, Medical & Scientific Relations, at the Alzheimer's Association. She directly manages several Alzheimer's Association initiatives, including the Research Roundtable, the World-Wide Alzheimer's Disease Neuroimaging Initiative, and the Global Alzheimer's Association Interactive Network. Dr. Carrillo is co-author of the National Institute on Aging–Alzheimer's Association revised criteria for the diagnosis of Alzheimer's and the Appropriate Use Criteria for Amyloid Imaging. In 2016, Dr. Carrillo joined the Governing Board of the Global Brain Health Institute, which supports a new generation of leaders to translate research evidence into effective policy and practice.

DEBRA L. CHERRY, PHD, is the Executive Vice President of Alzheimer's Greater Los Angeles. She received her PhD from the University of Southern California and completed a postdoctoral fellowship at the University of California, Los Angeles. She has helped design numerous award-winning programs, including El Portal Latino Dementia Care Network and its replication in African-American and Asian-American communities; the Dementia Cal MediConnect Project; and the caregiver activation program, Partnering with Your Doctor. She has published numerous articles on programs for these populations. Dr. Cherry recently joined the Advisory Council on Alzheimer's Research, Care, and Services, and she is on California's ADRD Advisory Committee. She is a recipient of the Rosalynn Carter Caregiving Award for leadership in this field.

SARA CZAJA, PHD, is the Leonard M. Miller Professor in the Department of Psychiatry and Behavioral Sciences, Director of the Center on Aging at the University of Miami, and Director of the Center on Research and Education for Aging and Technology Enhancement (CREATE). CREATE is funded by the National Institute on Aging and collaborates with the Georgia Institute of Technology and Florida State University. CREATE focuses on the interface between older adults and technology systems in work, healthcare, and living settings. Her research interests include aging, cognition, aging and healthcare access and service delivery, family caregiving, aging and technology, human-computer interaction, training, and functional assessment.

DAVANGERE P. DEVANAND, MD, is Director of the Division of Geriatric Psychiatry and a professor of Psychiatry and Neurology at Columbia University Medical Center. He is also Co-Director of the Memory Disorders Center and Co-Director of the Late Life Depression Clinic at the New York State Psychiatric Institute. He pioneered studies on the interface between depression and cognitive impairment in the elderly and is well-known for his research into early diagnostic markers of Alzheimer's disease and the treatment of psychosis and agitation in this disorder. Dr. Devanand has authored more than 280 publications and three books.

LEISA R. EASOM, PHD, RN, is Executive Director of the Rosalynn Carter Institute for Caregiving and Pope Eminent Scholar at Georgia Southwestern State University. Certified in gerontology, Dr. Easom focuses her research on caregivers (military and dementia), end-of-life issues, aging, and health promotion in rural areas of the United States. She has served on the Caregiving Advisory Panel for the U.S. Administration on Aging, the ARCH Expert Panel on Respite Research, and the Carter Center Task Force for Mental Health. She was recently selected as a Reynolds Center of Geriatric Nursing Excellence Distinguished Scholar in Aging.

THOMAS E. EDES, MD, MS, is Executive Director of Geriatrics and Extended Care for the U.S. Department of Veterans Affairs (VA). He has national responsibility for VA's spectrum of services for veterans of any age with serious, chronic, disabling diseases, including interdisciplinary care in clinics, hospitals, at home, in the community, in nursing homes, and through Geriatric Research Education and Clinical Centers. Under his leadership, the number of veterans receiving home-based primary care has quadrupled, palliative care is an established program in every VA medical center, and Medical Foster Home is a national program in 43 states and growing.

GARY EPSTEIN-LUBOW, MD, is a geriatric psychiatrist at Hebrew SeniorLife in Boston, MA, where he is Medical Director for the organization's planned center of excellence in Alzheimer's disease and memory care. At Brown University, Dr. Lubow is associate professor of Psychiatry and Human Behavior, associate professor of Health Services, Policy and Practice, and associate professor of Medical Science in the Teaching Scholar Track. Dr. Lubow's research interests include family caregiving and the development of quality measures for dementia care. He co-chaired the Summit Persons Living with Dementia Stakeholder Group and has recently completed a one-year Health and Aging Policy Fellowship.

SAM FAZIO, PHD, is Director of Quality Care and Psychosocial Research at the Alzheimer's Association. Dr. Fazio has worked for the national headquarters of the Alzheimer's Association since 1994 in a variety of areas, including Education and Training, Program Services, and Medical and Scientific Relations. He currently works in the Care and Support area, where he oversees quality care standards and social/behavioral research initiatives. Dr. Fazio received his doctorate in developmental psychology from Loyola University, Chicago. Prior to working for the Alzheimer's Association, Dr. Fazio worked for Rush Presbyterian St. Luke's Medical Center at the Alzheimer's Family Care Center, an adult day center specifically designed for people with dementia. He has worked in the field of aging since 1987 and has a broad range of experience, including research, leadership and management, working with older adults and families, and direct care. Dr. Fazio has presented both nationally and internationally as well as published numerous journal articles and book chapters. Dr. Fazio is the author of *The Enduring Self in People with Alzheimer's: Getting to the Heart of Individualized Care* and the co-author of the book *Rethinking Alzheimer's Care*.

RICHARD H. FORTINSKY, PHD, is a professor at the University of Connecticut School of Medicine, where he is based at the Center on Aging and holds the Health Net, Inc. Endowed Chair in Geriatrics and Gerontology. Dr. Fortinsky conducts research with community-based partners intended to improve care systems and health-related outcomes for older adults with dementia and their family caregivers. He presently serves as principal investigator for translational studies funded by the NIH/NIA and the Patient-Centered Outcomes Research Institute designed to test in-home, team-based interventions targeting older adults with dementia, depression, and delirium and their families.

LORI FRANK, PHD, has led the Evaluation and Analysis section at the Patient-Centered Outcomes Research Institute (PCORI). She also designed and led the PCORI Dementia Methods Pre-Summit. Her work has focused on patient-reported outcomes and inclusion of consumer perspectives in research. She served as the Executive Director at the Center for Health Outcomes Research, MEDTAP International/UBC, where she founded the Cognition Initiative of the Critical Path Institute PRO Consortium to develop measures for mild cognitive impairment. She serves on the Board of the International Society for Quality of Life Research and the Memory Screening Advisory Board of the Alzheimer's Foundation of America.

LISA FREDMAN, PHD, is professor and Director of Faculty Development at the Boston University School of Public Health. Her research focuses on the health effects of caregiving and predictors of functioning in older adults, with particular attention to psychological and behavioral factors associated with active lifespan. She has been the principal investigator of several NIH-funded studies on health outcomes of caregiving. Her research on the Healthy Caregiver Hypothesis has led to re-examination of the caregiver stress hypothesis, as well as advancing methods for epidemiologic studies of caregiving outcomes.

KAREN FREDRIKSEN GOLDSSEN, PHD, is a professor in the School of Social Work and Director of the Healthy Generations Hartford Center of Excellence at the University of Washington. Dr. Goldsen is an internationally recognized scholar addressing aging and health in historically disadvantaged communities. She is Principal Investigator of the Aging with Pride: National Health, Aging, and Sexuality/Gender Study and Co-Principal Investigator of Older Adults Living with Alzheimer's Disease and Caregivers in Underserved Populations. She has authored more than 100 journal publications, with research cited in leading news sources such as the *New York Times*, and she was recognized by PBS's Next Avenue as a Top 50 Influencer in Aging.

JOSEPH E. GAUGLER, PHD, is a long-term care professor in Nursing at the University of Minnesota. Dr. Gaugler's research examines the sources and effectiveness of long-term care for chronically disabled older adults. A developmental psychologist with an interdisciplinary research focus, Dr. Gaugler's interests include Alzheimer's disease and long-term care, the longitudinal ramifications of family care for disabled adults, and the effectiveness of community-based and psychosocial services for chronically ill adults and their caregiving families. Underpinning these substantive areas, Dr. Gaugler also has interests in longitudinal and mixed methods research.

ELIZABETH GOULD, MSW, is a senior researcher at RTI International and co-directs the National Alzheimer's and Dementia Resource Center (NADRC) funded by the Administration for Community Living (ACL). The NADRC provides expert technical assistance to ACL and its grantees and makes program information and resources available to other professionals. Ms. Gould has more than 25 years of experience in dementia care and recently contributed to several topic papers, including non-Alzheimer's caregiver experience, care coordination, and scaling up dementia services. Prior to coming to RTI International, Ms. Gould managed the quality care initiatives of the national Alzheimer's Association and the California Guideline for Alzheimer's Disease Management.

LISA GWYTHYER, MSW, LCSW, is a social worker with 39 years of experience working with individuals living with dementia and their families. She founded and directs the long-running Duke (Alzheimer's) Family Support Program in North Carolina. She has participated in numerous other government and private-sector initiatives to develop, implement, evaluate, and disseminate home, community-based, and residential care programs to improve quality of care and limit the negative outcomes of living with or caring for persons with dementia. She is an associate professor in the Department of Psychiatry and Behavioral Sciences at Duke University and was past president of The Gerontological Society of America.

SHARON HALL is a care partner to her 95-year-old mother, who has vascular dementia, and her husband, who has frontotemporal degeneration (FTD), both of whom live with her in Cumming, GA. Sharon is an active advocate for FTD. She is a support group facilitator and educator for the Association for Frontotemporal Degeneration. She holds an FTD chat on caregiving.com and hosts a monthly podcast called "Talking FTD With Geri," with Dr. Geri Hall from Banner Alzheimer's on blogtalkradio.com/caregiving. Sharon's motto is "I will not stop advocating until FTD means frontotemporal degeneration and not a company that brings you flowers."

TAMAR HELLER, PHD, Distinguished Professor, heads the Department of Disability and Human Development at the University of Illinois at Chicago and its University Center of Excellence in Developmental Disabilities. She also directs the Rehabilitation Research and Training Center (RRTC) on Developmental Disabilities and Health and is Co-Principal Investigator of the RRTC on the Family Support RTC. Her research focuses on health and long-term services and supports for individuals with disabilities and their families. She was President of the Association of University Centers on Disabilities Board, a delegate to the 2005 White House Conference on Aging, and co-founder of the national Sibling Leadership Network.

NANCY A. HODGSON, PHD, RN, FAAN, is the Anthony Buividas Endowed Term Chair of Gerontology, the Program Director for the Hillman Scholars Program in Nursing Innovation, and an associate professor in the Biobehavioral Health Sciences Department at the University of Pennsylvania School of Nursing. Her 30-plus-year nursing career has been dedicated to improving end-of-life experiences for cognitively and physically frail older adults. Her research focuses on the development and translation of biobehavioral interventions to ease symptom burden for persons with dementia and their family caregivers, and the physiological mechanisms underlying the effects of behavioral interventions to reduce symptom distress.

CYNTHIA HULING HUMMEL, PHD, BS, MDIV, DMIN, of Elmira, NY, is passionate about Alzheimer's research and has been participating in the Alzheimer's Disease Neuroimaging Initiative clinical study since 2010. She was diagnosed with amnesic mild cognitive impairment in 2011 and with Alzheimer's disease in 2016, and is active in the Rochester and Finger Lakes Chapter of the Alzheimer's Association. She served as an Alzheimer's Association National Early-Stage Advisor in 2015. Locally, she leads a support group and helps to coordinate and host social and educational events for those living with the disease. Cynthia is an active advocate and speaks regionally about living with Alzheimer's.

GAIL GIBSON HUNT is President and CEO of the National Alliance for Caregiving and an international expert on family caregiving. She served on the 2005 White House Conference on Aging's Policy Committee and the Centers for Medicare and Medicaid Services Advisory Panel on Medicare Education. She is a commissioner for the Center for Aging Services Technology, on the Board of the Long-Term Quality Alliance and the National Center for Creative Aging, and a member of the Multiple Chronic Conditions Workforce Technical Expert Workgroup. She co-chairs the National Quality Forum's Person- and Family-Centered Care Task Force and is on the Governing Board of the Patient-Centered Outcomes Research Institute.

LEE JENNINGS, MD, MSHS, an assistant professor at the Reynolds Department of Geriatric Medicine at the University of Oklahoma Health Sciences Center, is a geriatrician and health services researcher whose work focuses on improving care delivery and health outcomes for patients with dementia and their caregivers and on developing patient goals as patient-centered outcome measures for dementia care. Her work is supported by New Investigator Awards from the Alzheimer's Association and Presbyterian Health Foundation. She is Principal Investigator and Director of the Oklahoma Healthy Aging Initiative, supported by a grant from the Reynolds Foundation, and is the 2017-18 Chair for the American Geriatrics Society Junior Faculty Research Special Interest Group.

HARRY JOHNS is the President and CEO of the Alzheimer's Association, the global leader in Alzheimer's and dementia information, advocacy, research, and support. The Association plays a leading role in making Alzheimer's a national priority, from nearly tripling research funding at the National Institutes of Health to securing Medicare coverage of care planning. Harry was appointed by the Secretary of Health and Human Services in 2011 to serve on the Advisory Council on Alzheimer's Research, Care, and Services. Following the 2013 G8 Dementia Summit, he was named to the World Dementia Council. He also serves as CEO of the Alzheimer's Impact Movement and is on the Board of Research!America.

KATHERINE S. JUDGE, PHD, is a professor in the Department of Psychology at Cleveland State University and a researcher at the Benjamin Rose Institute on Aging. Her research focuses on developing, implementing, and evaluating cognitive rehabilitative, psychosocial skills training, and care-coordination models for individuals with cognitive impairment, their family caregivers, and healthcare providers. These protocols positively impact a wide range of well-being, strain, coping, and functional outcomes. Additionally, her research seeks to understand the illness experience associated with cognitive impairment for individuals living with dementia, stroke, and/or traumatic brain injury, and methods for including individuals with cognitive impairment in the research process.

HELEN KALES, MD, PPA, is a professor of Psychiatry at the University of Michigan and a research investigator in the Center for Clinical Management Research and Geriatric Research Education and Clinical Center at the VA Ann Arbor Health System. A fellowship-trained, board-certified geriatric psychiatrist, her research is directly informed by her clinical work and experiences with patients, families, providers, and systems to diminish the barriers to effective and high-quality care for older people. She is recognized as a national and international expert in outcomes related to later-life depression and risks of antipsychotic and other psychotropic medications in older adults, and in researching ways to improve dementia care.

EDWARD K. KAPLAN, PHD, is the Key and Hortense Kaiserman Professor in the Humanities Emeritus at Brandeis University, where he taught French and comparative literature from 1978 to 2015. He published numerous articles, reviews, and books, including books on Jules Michelet, the French historian, and Charles Baudelaire, the poet and critic. Dr. Kaplan is especially interested in the relationship between the aesthetic, ethical, and religious dimensions of human experience. He was diagnosed with Lewy body disease in 2013. His symptoms are progressing slowly, allowing him to continue professional work. He lives in Waltham, MA, with his wife Janna Kaplan.

JANNA KAPLAN, MSC, is a research neuroscientist at Brandeis University. She came to the United States in 1982 as a Jewish refugee from the former Soviet Union and married Edward Kaplan, a humanities professor at Brandeis. Edward, now 75, was diagnosed with Lewy body disease in 2013. Janna has been his caregiver since diagnosis. She was diagnosed with breast cancer in 2014, and while in treatment, continued to provide care for Edward, her elderly parents, and a sick brother. Her parents and brother died within the past 3 years. Healthy now, Janna is Edward's primary caregiver, as well as a scientist, mother, and grandmother.

JASON KARLAWISH, MD, is a professor of Medicine, Medical Ethics, and Health Policy, and Neurology at the University of Pennsylvania and Co-Director of the Penn Memory Center. His research focuses on ethical and policy issues encountered in research and care that engages older adults with late-life cognitive disorders such as Alzheimer's disease and cognitive aging. He is currently examining the clinical and social impacts of changing concepts of Alzheimer's disease. He developed the concept of "whealthcare," a novel model to promote cognitive health and maintain wealth with a particular focus on the banking and financial services industries (www.whealthcare.org).

JEFFREY KAYE, MD, is the Layton Professor of Neurology and Biomedical Engineering at Oregon Health & Science University (OHSU). He directs ORCATECH—the Oregon Center for Aging & Technology—the NIA-Layton Aging & Alzheimer's Disease Center at OHSU, and the recently established Collaborative Aging Research Using Technology initiative. He serves on many national and international panels and boards in the fields of geriatrics, neurology, and technology, is an author of more than 400 scientific publications, and holds several major grant awards from federal agencies, national foundations, and industrial sponsors.

AMY M. KILBOURNE, PHD, MPH, is Director of the VA Quality Enhancement Research Initiative and a professor of Psychiatry at the University of Michigan. She is a national expert in implementation science, academic-community partnerships, and healthcare pragmatic clinical trials in healthcare systems. Dr. Kilbourne's research has led to several national initiatives, including a population management program for veterans with serious mental illness, integrated physical and mental healthcare models, and a health disparities research roadmap. She is the recipient of several awards, including the Presidential Early Career Award for Scientists and Engineers and the Depression and Bipolar Support Alliance Gerald Klerman Award.

ANN KOLANOWSKI, PHD, RN, FGSA, FAAN, is a professor of Nursing at the College of Nursing and a professor of Psychiatry at the College of Medicine, Pennsylvania State University. Dr. Kolanowski conducts research on psychosocial interventions for behaviors and cognitive symptoms exhibited by people living with dementia. Her work has been supported by grants from the National Institutes of Health, Alzheimer's Association, Hartford Foundation, and Commonwealth Foundation. Dr. Kolanowski has published more than 120 papers in scientific journals. She is a fellow of the American Academy of Nursing, The Gerontological Society of America, and is the founding Director of the Hartford Center of Geriatric Nursing Excellence at Penn State University.

IAN KREMER, JD, is Executive Director of the LEAD Coalition (Leaders Engaged on Alzheimer's Disease), unifying more than 90 local, state, national, and multinational organizations committed to stopping Alzheimer's disease and other dementias, including vascular and Lewy body dementia and frontotemporal degeneration. The coalition works collaboratively to focus the nation's strategic attention on accelerating transformational progress in quality of life for persons with dementia and their caregivers; detection and diagnosis; and research leading to prevention, effective treatment, and eventual cures. Ian holds degrees from Washington University and the University of Michigan School of Law and has worked on dementia policy since 1996.

KEN LANGA, MD, PHD, is the Cyrus Sturgis Professor of Medicine in the Department of Internal Medicine, Institute for Social Research, and Veterans Affairs Center for Clinical Management Research, all at the University of Michigan. He is the Associate Director of the Health and Retirement Study, a longitudinal, nationally representative study of 20,000 U.S. adults, funded by the National Institute on Aging. Dr. Langa's research focuses on the epidemiology and costs of Alzheimer's disease and dementia. He is currently studying population trends in dementia incidence and prevalence, as well as the relationship of cardiovascular risk factors to cognitive decline and dementia.

DEBRA LAPPIN, JD, serves as a principal with Faegre Baker Daniels Consulting, where she leads the health and biosciences team, and as counsel with Faegre Baker Daniels. She consults with public, private, and nonprofit entities across the life science sector. Today her work focuses in large part on Alzheimer's as she serves as Senior Advisor to UsAgainstAlzheimer's. She has served on advisory boards to the directors of both the National Institutes of Health and the Centers for Disease Control and Prevention, as President of the Council for American Medical Innovation, and continuing today as a member of the Board of Research!America.

SHARI M. LING, MD, is the Centers for Medicare and Medicaid Services Deputy Chief Medical Officer, serving in the Center for Clinical Standards and Quality, where she is responsible for assisting the Chief Medical Officer in the pursuit of higher quality health care, healthier populations, and lower cost through quality improvement. Dr. Ling's long-standing focus is on improving health outcomes through delivery of high quality, beneficiary-centered care across all care settings, with a special interest in the care of persons with multiple chronic conditions and functional limitations. Dr. Ling is the clinical subgroup lead for the Advisory Council on Alzheimer's Research, Care, and Services.

SARAH LENZ LOCK, JD, is Senior Vice President for Policy in AARP Policy, Research, and International Affairs, where she helps position AARP as a thought leader addressing the major issues facing older Americans. She leads AARP's policy initiatives on brain health and care for people living with dementia and is the Executive Director of the Global Council on Brain Health, an independent collaborative convened by AARP to bring together scientists, health professionals, scholars, and policy experts from around the world to develop the best possible advice about what older adults can do to maintain and improve their brain health.

CONSTANTINE LYKETSOS, MD, MHS, DFAPA, FAPM, FACNP, directs the Johns Hopkins Memory and Alzheimer's Treatment Center and is Associate Director of the Alzheimer's Disease Research Center. A world expert in the treatment of Alzheimer's and dementia, Dr. Lyketsos leads research on treatment development for Alzheimer's disease and efforts to ensure provision of state-of-the-art dementia care for patients in the community. He has received several major international awards recognizing his accomplishments. He has authored or co-authored more than 350 journal articles, chapters, and commentaries, as well as five books. He has been named one of America's Top Doctors since 2001.

JENNIFER MANLY, PHD, is an associate professor of Neuropsychology in Neurology at the Taub Institute for Research in Alzheimer's Disease and the Aging Brain at Columbia University. Her research focuses on mechanisms of disparities in cognitive aging and Alzheimer's disease. She received Early Career awards from the Society for Clinical Neuropsychology and from the National Academy of Neuropsychology, received the Tony Wong Diversity Award for Outstanding Mentorship, and is an APA Fellow. She served on the Alzheimer's Association Medical & Scientific Research Board and the Advisory Council on Alzheimer's Research, Care, and Services.

OANH MEYER, PHD, MAS, is an assistant professor in the Department of Neurology at the University of California, Davis, School of Medicine. She is Associate Director of the Research Education Component at the UC-Davis Alzheimer's Disease Center. Dr. Meyer received her PhD in Social Psychology and her master's in Advanced Study in Clinical Research at UC-Davis. Her current research interests include culturally appropriate dementia caregiving interventions, social determinants of cognitive decline associated with dementia, and geographic disparities in cognitive and mental health for older adults.

MARY MITTELMAN, DPH, is Director of the Alzheimer's Disease and Related Dementias Family Support Program and a Research Professor at New York University (NYU) School of Medicine. She has been developing and evaluating psychosocial interventions for people with cognitive impairment and their families for three decades. She was the Principal Investigator of the NIH-funded study of the NYU Caregiver Intervention, which has won many awards and been widely replicated. Dr. Mittelman is also the founder of a chorus for people with dementia with their family members that named themselves the Unforgettables. It rehearses and gives regular concerts at Saint Peter's Church in Manhattan.

BRIAN MITTMAN, PHD, is a senior research scientist at Kaiser Permanente Southern California and Senior Scientist at the VA Center for Healthcare Innovation, Implementation, and Policy and VA Quality Enhancement Research Initiative. His research interests include healthcare implementation and improvement science and healthcare delivery science. He has additional affiliations at RAND and the University of California, Los Angeles, where he co-leads the CTSI Implementation and Improvement Science Initiative. He serves on the PCORI Methodology Committee and Association of American Medical Colleges Advisory Panel on Research, as well as advisory boards for several U.S. and international research programs in implementation science.

VINCENT MOR, PHD, is the Florence Pirce Grant Professor of Community Health at Brown University's School of Public Health and a Providence VA Medical Center senior health scientist. Principal Investigator of more than 40 NIH grants and author of more than 400 peer-reviewed articles, he received a Robert Wood Johnson Foundation Health Policy investigator award and a National Institute on Aging MERIT award. He was one of the authors of the congressionally mandated MDS for nursing home resident assessment. Dr. Mor served on the Academy Health Board and received its Distinguished Investigator Award and the Agency for Healthcare Research and Quality Eisenberg Mentorship Award, NHPCO Distinguished Researcher Award, and is a member of the National Academy of Medicine.

DARBY MORHARDT, PHD, LCSW, is an associate professor for the Cognitive Neurology and Alzheimer's Disease Center and Department of Preventive Medicine, Northwestern University Feinberg School of Medicine. Dr. Morhardt has more than 30 years of clinical experience with cognitively impaired individuals and their families. Her research is focused on the experience of individuals and families living with dementia, the process of tailoring care to needs and symptoms, and the development and evaluation of support and educational interventions. She also partners with under-represented communities to raise dementia awareness, identify service and education needs, and promote research participation.

LINDA NICHOLS, PHD, is a medical anthropologist and health services researcher at the Memphis VA Medical Center and a professor of Preventive and Internal Medicine at the University of Tennessee Health Science Center. With her colleague Dr. Jennifer Martindale-Adams, she is the Co-Director of the VA's national Caregiver Center and the University's Caregiver Center. The Centers develop and evaluate caregiving interventions, train staff to work with caregivers, and work with caregivers across the country. Her research is currently funded by the VA, Department of Defense/U.S. Army, and the Rx Foundation. Her major interest is implementation of caregiving interventions into practice.

BRENDA NICHOLSON, MD, is a retired medical oncologist. After completing fellowship training, she worked as an assistant professor at Vanderbilt University. She was Director of the Clinical Breast Cancer Program and a medical oncologist with Tennessee Cancer Specialists in Knoxville. In 2014, Dr. Nicholson was diagnosed with Alzheimer's disease at the age of 49. She has worked as an advocate through her participation in the Memory Cafe at Alzheimer's Tennessee in Knoxville and speaking at the 30th Annual Disease Management & Research Symposium. She also helped St. John Neumann Catholic Church develop and implement the St. Joseph's Caregiver Ministry to assist family caregivers.

GREG O'BRIEN has more than 35 years of experience as a writer, editor, investigative reporter, and publisher. In 2009, at the age of 59, Greg was diagnosed with younger-onset Alzheimer's. Greg's mother, father, paternal uncle, and maternal grandfather all died with symptoms of dementia. After receiving the diagnosis, Greg decided to focus on raising awareness of the early-stage experience. In 2015, he became a member of the Alzheimer's Association National Early-Stage Advisory Group, and he continues to advocate, stating, "I want to help teach the world how to live and speak through the heart as the brain diminishes."

LISA ONKEN, PHD, directs the Behavior Change and Interventions Program at the National Institute on Aging (NIA). Prior to joining NIA, Dr. Onken served as Chief of the Behavioral and Integrative Treatment Branch and Associate Director for Treatment at the National Institute on Drug Abuse. Dr. Onken received her PhD in clinical psychology from Northwestern University. She is a fellow of the Association for Psychological Science and a consulting editor for the journal *Clinical Psychological Science*. She has led numerous trans-NIH initiatives related to behavioral intervention development.

RONALD C. PETERSEN, MD, PHD, is a professor of Neurology, the Cora Kanow Professor in Alzheimer's Disease Research, and a Mayo Clinic Distinguished Investigator. Past and current positions include serving on the Board of Directors of the Alzheimer's Association; as Chair of the Advisory Council on Alzheimer's Research, Care, and Services; and as Chair of the World Dementia Council. Dr. Petersen is a recipient of the 2004 MetLife Award for Medical Research in Alzheimer's Disease and the 2005 Potamkin Prize for Research in Pick's, Alzheimer's, and Related Disorders of the American Academy of Neurology. He has published more than 800 peer-reviewed papers and edited five books.

LOUISE PHILLIPS, MD, is a retired physician and former medical director of Village Care of New York. She spent the majority of her career as an HIV/AIDS advocate in hospital and clinic settings and was responsible for a study of AIDS Dementia Care for the New York State Health Department. Dr. Phillips was diagnosed with Lewy body dementia in 2015 and is an advocate through the Lewy Body Dementia Association. She is a member of the Summit Persons Living with Dementia Stakeholder Group and hopes to raise awareness of the diverse perspectives and individual needs of those affected by cognitive impairment.

JAMES PICKETT, PHD, is Head of Research at the Alzheimer's Society, which delivers care and support for people with dementia across the United Kingdom and funds research spanning biomedical and social science. In 1999, the Alzheimer's Society set up an innovative program of involving people affected by dementia in research. Dr. Pickett leads the development of research initiatives, funding, and partnerships. He has worked at the Alzheimer's Society since 2009 and previously completed a PhD in molecular pharmacology from the University of Cambridge.

BARBARA RESNICK, PHD, RN, CRNP, FAAN, FAANP, is a professor in the Department of Organizational Systems and Adult Health at the University of Maryland School of Nursing. She co-directs the Adult/Gerontological Nurse Practitioner Program and the Biology and Behavior Across the Lifespan Research Center of Excellence, holds the Sonya Ziporkin Gershowitz Chair in Gerontology, and does clinical work at Roland Park Place. Her research program is focused on optimizing function and physical activity among older adults, exploring resilience and genetics on function and physical activity, and testing dissemination and implementation of interventions in real-world settings. She has more than 200 published articles and has held leadership positions in national nursing, gerontological, and geriatrics organizations.

DAVID B. REUBEN, MD, is Director of the Multicampus Program in Geriatrics Medicine and Gerontology and is chief of the Division of Geriatrics at the University of California, Los Angeles (UCLA). He is the Archstone Foundation Chair and professor at the David Geffen School of Medicine at UCLA and director of the UCLA Alzheimer's and Dementia Care program. Dr. Reuben received one of the first CMMI Innovations Challenge awards to develop a model program to provide comprehensive, coordinated care for patients with Alzheimer's disease and other dementias. He also recently completed a grant to determine and measure patient and caregiver goals in Alzheimer's disease and dementia.

JULIE ROBISON, PHD, is a professor of Medicine in the Center on Aging at the University of Connecticut School of Medicine. She conducts evidence-based health services research and intervention studies focused on aging families; long-term services, supports, and policy; and dementia and health disparities using quantitative and qualitative research methods. She completed her PhD at Cornell University and a postdoctoral fellowship in the epidemiology of aging at the Yale School of Medicine. The results of her work directly impact the implementation of policies and programs that serve extremely vulnerable populations in Connecticut and nationally.

QUINCY MILES SAMUS, PHD, MS, is an associate professor in the Department of Psychiatry and Behavioral Sciences at Johns Hopkins School of Medicine. She is an applied gerontologist, trained in epidemiology, behavioral interventions development and evaluation, and health services research. The goal of her work is to improve quality of care and outcomes for persons with dementia and their families through development of evidence-based dementia interventions and translation into practice.

MELANIE (LONNI) SCHICKER, EDD, MHSA, RN, is a nurse who has spent much of her career in the burn ICU and as a director of both healthcare quality and case management. She was an associate professor of Health Administration, writing and initiating a master's of health administration program. In 2014, at the age of 59, Dr. Schicker was diagnosed with cognitive impairment. No longer able to effectively function in her work with students, she has devoted her time and energy to bringing attention to the plight of those with Alzheimer's and related dementias. Dr. Schicker is co-chair of the Summit Persons Living with Dementia Stakeholder Group.

MARK SNOWDEN, MD, MPH, is an associate professor in the University of Washington School of Medicine, Department of Psychiatry and Behavioral Sciences. He received his MD and MPH from the University of Washington, where he also completed psychiatric residency training and the geriatric psychiatry fellowship. He is Chief of Psychiatry of Harborview Medical Center and provides and supervises geriatric psychiatry services to community-based nursing homes and clinics. His research focuses on delivery of evidence-based mental health services to community-dwelling older adults and nursing home residents. He led several expert panels in formulating recommendations for dissemination of evidence-based practices for depression and other mental health conditions.

ALAN B. STEVENS, PHD, holds the Vernon D. Holleman–Lewis M. Rampy Centennial Chair in Gerontology at Baylor Scott & White Health (BSWH). He serves as director of the Center for Applied Health Research, a BSWH system-wide center dedicated to population health management via healthcare delivery and implementation science research. Dr. Stevens is nationally recognized for his contributions to the fields of gerontology, dementia caregiving, care transitions, and evaluation of community-based health programs such as Meals on Wheels. Dr. Stevens is a Fellow of the American Psychological Association and The Gerontological Society of America.

NORA SUPER, MPA, is Chief of Programs and Services for the National Association of Area Agencies on Aging (n4a). She oversees n4a's initiatives and resource centers on integrated care, managed long-term services and supports, transportation, volunteerism, and the Eldercare Locator. Nora is a lead for the Dementia Friendly America Initiative to effectively support and serve those living with dementia and family and friend care. Before joining n4a, Nora was Executive Director of the 2015 White House Conference on Aging, where she directed a nationwide effort to identify and advance actions to improve the quality of life of older Americans.

ZALDY S. TAN, MD, MPH, is Medical Director of the University of California, Los Angeles (UCLA) Alzheimer's and Dementia Care Program and Assistant Dean for Curricular Affairs at the David Geffen School of Medicine, UCLA. He is the director and Principal Investigator for the UCLA Geriatric Workforce Enhancement Program, the TimeOut Intergenerational Program, and the Improving Caregiving for Dementia (I-CareD) Project. Dr. Tan holds the Philo Van Wagoner Endowed Chair in Geriatric Medicine and is Associate Chief at the UCLA Department of Medicine, Division of Geriatric Medicine. He performs epidemiological research at the Framingham Heart Study and quality improvement and health services research at UCLA.

ANGELA TAYLOR is the director of Programs at the Lewy Body Dementia Association (LBDA). Mrs. Taylor oversees all research, advocacy, and educational initiatives at the LBDA. Bringing a personal connection to Lewy body dementia as a family caregiver for her father, she is regularly invited to speak to lay and professional audiences as well as the media on the impact of LBD. A nationally recognized LBD advocate, she serves on the Advisory Council on Alzheimer's Research, Care, and Services. In 2015, she was recognized for her contributions on behalf to the LBD community at the International Dementia with Lewy Bodies Conference.

LINDA TERI, PHD, is a professor at the University of Washington, author of more than 350 publications, and recipient of The Gerontological Society of America's prestigious M. Powell Lawton Award for "significant innovation in gerontological treatment that improves the lives of older persons." Her work focuses on improving dementia care by developing effective interventions and ensuring they are readily available for others to implement and scale up, locally, nationally and globally. Her groundbreaking interventions for persons living with dementia, families, staff, and healthcare professionals have been widely cited as exemplars of evidence-based programs that are ready for dissemination into the community.

SOWANDE TICHAWONNA is an award-winning, independent filmmaker and actor in Washington D.C. He was a caregiver for his mother, who died of Alzheimer's disease in 2013, and is a caregiver for his teenage son, who has Down syndrome. He has been a member of the Advisory Council on Alzheimer's Research, Care, and Services since 2015. Mr. Tichawonna's acting credits include starring roles in the stage play *For the Love of Oscar* and the ID series *Who the Bleep Did I Marry?* His film credits include *The New "N" Word*, a YouTube Web series that has viewership in more than 25 countries spanning five continents.

GEORGE VRADENBURG is Chairman of UsAgainstAlzheimer's, which he co-founded with his wife, Trish Vradenburg, in October 2010, and Chair of the Global Alzheimer's Platform Foundation, which he founded in 2013. Mr. Vradenburg also convened the Global CEO Initiative on Alzheimer's Disease, a public-private partnership of leading global corporations and nonprofit and governmental organizations to identify and advance high-priority activities necessary to prevent and treat Alzheimer's disease by 2025 and improve quality of life for all affected by the disease. He served on the Advisory Council on Alzheimer's Research, Care, and Services and has testified before Congress about the global Alzheimer's pandemic.

STEVE WARING, DVM, PHD, is a senior research scientist with the Essentia Institute of Rural Health (EIRH) in Duluth, MN. His current research interests focus on the epidemiology of Alzheimer's disease and dementia, decision support tools for transforming healthcare delivery, and precision medicine. He currently co-leads a systems change initiative to improve dementia care across Essentia. Dr. Waring is Chair of the Governing Board for the Health Care Systems Research Network, is an investigator on several studies to improve health in elderly populations, and serves on several steering committees focused on aging, including the ACT on Alzheimer's-funded Dementia-Friendly Duluth initiative.

GREGG WARSHAW, MD, is a professor of Family Medicine and Internal Medicine at the University of North Carolina at Chapel Hill. Dr. Warshaw was previously director of the Geriatric Medicine Program at the University of Cincinnati from 1987 to 2015. Dr. Warshaw's academic interests include geriatric medicine education, clinical care of Alzheimer's disease, and the geriatric medicine workforce. From 2001 to 2012, he directed the American Geriatrics Society (AGS)/ADGAP Geriatric Medicine Physician Workforce study. Dr. Warshaw was a 2013-2014 Health and Aging Policy Fellow/APSA Congressional Fellow. He is a past president of the AGS and the Association of Directors of Geriatric Academic Programs.

TERESA WEBB, RN, was an RN Clinical Manager before being diagnosed with primary progressive aphasia in 2010. Ms. Webb is founder and chair of the nonprofit Frontotemporal Dementia Advocacy Resource Network, created by those diagnosed with FTD for those with FTD. She is an active member of the Association for Frontotemporal Degeneration Think Tank and the nonprofit To Whom I May Concern, where she participated in numerous live performances and starred in the first film production of *This Is My Voice*. Ms. Webb is Co-Chair of the Summit Persons Living with Dementia Stakeholder Group.

SANDRA WEINTRAUB, PHD, is a professor of Psychiatry and Behavioral Sciences and Neurology at Northwestern Feinberg School of Medicine and director of the Clinical Core of the NIA-funded Cognitive Neurology and Alzheimer's Disease Center. She served on the Alzheimer's Disease Clinical Task Force to standardize data collection at all 30-plus centers funded by the NIA across the United States and helped revise the 2011 criteria for the clinical diagnoses of dementia of the Alzheimer type, behavioral variant frontotemporal dementia, and primary progressive aphasia. Dr. Weintraub has authored more than 200 articles and book chapters on the neuropsychology of dementia, cognitive aging, and aphasia.

CAROL J. WHITLATCH, PHD, is assistant director of the Center for Research and Education at the Benjamin Rose Institute on Aging in Cleveland, OH. She is also an adjunct associate professor of Sociology at Case Western Reserve University. Her research focuses on the development, evaluation, and translation of person- and family-centered interventions in early-stage dementia. Her work also examines healthcare choice and decision making in caregiver-person with dementia dyads, and autonomy and functioning in diverse caregiving families. Currently, Dr. Whitlatch is involved in developing evidence-based dyadic interventions for families facing the challenges of early-stage dementia and other chronic conditions.

MARY E. WORSTELL, MPH, is a senior advisor to the Deputy Assistant Secretary for Health, focused on expanding policies and programs to address the growing health and safety needs of older adults. She also advises the U.S. Department of Health and Human Services Office on Women's Health on health disparities for older women. In 2015, she co-directed the Healthy Aging Workforce and Caregivers Forum for the White House Conference on Aging. From 2007 to 2010, she was Group Director at the Centers for Medicare and Medicaid Services. During her 40-year career, Ms. Worstell has held leadership positions within federal, nonfederal, and international health standard-setting boards.

SHERYL ZIMMERMAN, PHD, is the Mary Lily Kenan Flagler Bingham Distinguished Professor at the School of Social Work, University of North Carolina at Chapel Hill. She is widely recognized as a leading expert in long-term services and supports for older adults, especially residential care. Key among her efforts are clinical trials and quality improvement projects to improve dementia care and outcomes. Dr. Zimmerman has received two career awards from the NIH, written four books and more than 300 manuscripts, and is Co-Editor-in-Chief of *JAMDA: The Journal of Post-Acute and Long-Term Care Medicine*. In 2016, Dr. Zimmerman was recognized as the nation's top-ranked social work scholar in aging. Currently, she is working with the Alzheimer's Association to develop its 2018 dementia care practice recommendations.

NATIONAL RESEARCH SUMMIT ON CARE, SERVICES, AND SUPPORTS FOR PERSONS WITH DEMENTIA AND THEIR CAREGIVERS

HELPFUL TIPS

Lunch Breaks

Day 1, October 16: 12:30 p.m.– 1:30 p.m.

Day 2, October 17: 12:30 p.m.–1:30 p.m.

Lunch will be served immediately outside the auditorium, on the lower level of Natcher, on both days of the Summit.

Where to Eat

Food is NOT allowed in the auditorium. Tables are available in the atrium above the auditorium. You may also eat in the dining room of the cafeteria or in other public areas, including the picnic tables outside, weather permitting.

Quiet Room

The Quiet Room is a respite space reserved for persons living with dementia. Please follow signage or ask a volunteer where to find this room.

Low-Stimulus Room

The Low-Stimulus Room is a reserved space for any guests who prefer to watch the videocast of the Summit. This room is located upstairs in Balcony A.

Social Media

#DementiaCareSummit

Video, Photography, Social Media Disclosure

This Summit, “National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers,” is a public meeting. The Summit proceedings are being video recorded, photographed, audio recorded, and closed captioned. By attending this meeting, you grant permission to the National Institutes of Health (NIH) and the Foundation for the National Institutes of Health (FNIH) to record the Summit proceedings through these means and to reproduce, copy, or distribute worldwide any such audio, video, and photography for the purpose of education and information via the Internet, Intranets, print, and social and other media platforms. Please be advised that the news media may attend and report from all presentations. Also, in this public venue, attendees are permitted to capture images and comments of speakers and meeting participants via the use of personal mobile devices, including telephones and tablets, and utilize forms of social media (Twitter, Facebook, Instagram, etc.) to disseminate these images and comments. These activities are not under NIH or FNIH control.

Online Resources

For online resources, please visit our official page: <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>

SUMMIT STEERING COMMITTEE MEMBERS

Co-Chairs

Laura N. Gitlin, PhD, Johns Hopkins University

Katie Maslow, MSW, The Gerontological Society of America

Executive Committee

Ronald C. Petersen, MD, PhD, Mayo Clinic College of Medicine

Ruth Katz, MA, Office of the Assistant Secretary for Planning & Evaluation (ASPE)

Rohini Khillan, MPH, Office of the Assistant Secretary for Planning & Evaluation (ASPE)

Committee Members

Gary Epstein-Lubow, MD, Brown University/Hebrew SeniorLife

Lori Frank, PhD, Patient-Centered Outcomes Research Institute

Richard Hodes, MD, National Institute on Aging

Ian Kremer, JD, LEAD Coalition (Leaders Engaged on Alzheimer's Disease)

Shari M. Ling, MD, Centers for Medicare and Medicaid Services

Sarah Lenz Lock, JD, AARP

Helen M. Matheny, MS, APR Collaborative Relations and Initiatives, West Virginia University Health Sciences Center

Lisa McGuire, PhD, Centers for Disease Control and Prevention

Jennifer Mead, MPH, Aging & People with Disabilities, Oregon Department of Human Services

Linda Nichols, PhD, Memphis VA Medical Center

Douglas Pace, NHA, Alzheimer's Association

Melanie (Lonni) Schicker, EdD, MHSA, RN, Persons Living with Dementia Stakeholder Group

Jane Tilly, DrPH, Administration for Community Living

Lois A. Tully, PhD, National Institute of Nursing Research

Teresa Webb, RN, Persons Living with Dementia Stakeholder Group

Joan Weiss, PhD, RN, Division of Medicine and Dentistry, Designated Federal Official, ACICBL, Health Resources and Services Administration

SUMMIT CROSS-CUTTING CHAIRS

Cross-Cutting Chair for Technology

Sara Czaja, PhD, University of Miami

Cross-Cutting Chair for Race, Ethnicity, and Culture

Ladson Hinton, MD, University of California, Davis

Cross-Cutting Chair for Etiologies and Disease Stage

Angela Taylor, Lewy Body Dementia Association

Cross-Cutting Chairs for Women's Issues

Mary E. Worstell, MPH, U.S. Department of Health and Human Services, Office of the
Assistant Secretary for Health

Jill Lesser, JD, WomenAgainstAlzheimer's

SUMMIT STAKEHOLDER GROUPS

Family Caregivers—Co-Chairs

Gail Gibson Hunt, National Alliance for Caregiving
Laurie G. Lindberg, The Gerontological Society of America
Donna Walberg, Minnesota Board of Aging

Persons Living with Dementia—Co-Chairs

Gary Epstein-Lubow, MD, Brown University/Hebrew SeniorLife
Melanie (Lonni) Schicker, EdD, MHSA, RN, Persons Living with Dementia Stakeholder Group
Emily Shubeck, LSW, Alzheimer's Association
Teresa Webb, RN, Persons Living with Dementia Stakeholder Group

Payers—Co-Chair

Elizabeth Goodman, DrPH, JD, MSW, Executive Office of Elder Affairs and MassHealth, Commonwealth of Massachusetts

State Programs—Co-Chairs

David Hoffman, DPS, CCE Bureau of Community Integration and Alzheimer's Disease, New York State Department of Health
Helen M. Matheny, MS, APR Collaborative Relations and Initiatives, West Virginia University Health Sciences Center
Jennifer Mead, MPH, Aging & People with Disabilities, Oregon Department of Human Services

Service Providers—Co-Chairs

Sarah Lenz Lock, JD, AARP
Douglas Pace, NHA, Alzheimer's Association

Workforce Development—Co-Chairs

Elyse Perweiler, MPP, RN, Rowan University School of Osteopathic Medicine
Nina Tumosa, PhD, Health Resources and Services Administration
Joan Weiss, PhD, RN, Division of Medicine and Dentistry, Designated Federal Official, ACICBL, Health Resources and Services Administration

PRE-SUMMIT ACTIVITIES

Scientific meetings were conducted prior to the Summit to:

- Provide foundational knowledge
- Offer specific recommendations to be presented and/or discussed at the Summit
- Provide working documents (white papers)
- Leverage and link existing scientific activity relevant to the Summit

Alzheimer's Association

Psychosocial Outcome Measures in Dementia Care

Pre-Summit Organizers

- Sam Fazio, PhD, Alzheimer's Association
- Beth Kallmyer, MSW, Alzheimer's Association

This pre-Summit will be discussed by Sam Fazio in Summit Session VI.

BrightFocus Foundation

Accelerating Development, Testing, and Dissemination of Home-Based Dementia Care Interventions

Pre-Summit Organizers

- Constantine Lyketsos, MD, MHS, DFAPA, FAPM, FACNP, Johns Hopkins School of Medicine
- Quincy Miles Samus, PhD, MS, Johns Hopkins School of Medicine

This pre-Summit will be discussed by Constantine Lyketsos in Summit Session I.

Council for the Advancement of Nursing Science, American Academy of Nursing

Systematic Review of Determinants of Behavioral Symptoms

Pre-Summit Organizer

- Ann Kolanowski, PhD, RN, FGSA, FAAN, Pennsylvania State University

This pre-Summit will be discussed by Helen Kales, MD, PPA, in Summit Session I.

National Alliance on Caregiving and the Alzheimer's Association

Dementia Caregiving in the United States: A Secondary Data Analysis of the Caregiving in the U.S. 2015 Report

Pre-Summit Organizers

- Gail Gibson Hunt, National Alliance for Caregiving
- Grace Whiting, JD, National Alliance for Caregiving

This pre-Summit will be discussed by Gail Hunt in Summit Session II.

National Institute on Aging

Innovating the Next Generation of Dementia and Alzheimer's Disease Care Interventions: Addressing the Needs of Persons Living with Dementia, Caregivers, and Care Providers

Pre-Summit Organizers

- John Haaga, PhD, National Institute on Aging, Division of Behavioral and Social Research
- Elena Fazio, PhD, National Institute on Aging, Division of Behavioral and Social Research
- Lisa Onken, PhD, National Institute on Aging, Division of Behavioral and Social Research

This pre-Summit will be discussed by Vincent Mor, PhD, in Summit Session II.

National Task Group on Intellectual Disabilities and Dementia Practices, Rehabilitation Research and Training Center in Developmental Disabilities and Health, University of Illinois at Chicago, and the Alzheimer's Association

Caregiving and Intellectual/Developmental Disabilities: Caregivers of Persons with Intellectual and Developmental Disabilities and Dementia

Pre-Summit Organizers

- Matthew Janicki, PhD, University of Illinois at Chicago
- Tamar Heller, PhD, University of Illinois at Chicago

This pre-Summit will be discussed by Tamar Heller in Summit Session I.

Patient-Centered Outcomes Research Institute (PCORI)

Methodological Considerations in Research on Dementia Care and Services

Pre-Summit Organizer

- Lori Frank, PhD, Patient-Centered Outcomes Research Institute (PCORI)

This pre-Summit will be discussed in three Summit Sessions: by Lori Frank in Summit Session III; by Darby Morhardt, PhD, LCSW, and Lisa Gwyther, MSW, LCSW, in Summit Session IV; and by Brian Mittman, PhD, in Summit Session VI.

University of California, Davis

Diversity and Alzheimer's Disease Caregiving

Pre-Summit Organizers

- Ladson Hinton, MD, University of California, Davis
- Oanh Meyer, PhD, MAS, University of California, Davis

This pre-Summit will be discussed by Oanh Meyer in Summit Session II.



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