

National Research Summit on

Care, Services, and Supports for Persons with Dementia and Their Caregivers

Summit Virtual Meeting Series

July 10, July 21, and August 13, 2020

National Institute on Aging, National Institutes of Health



National Institute
on Aging



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Goal of the Summit

The goal of the summit is to bring together individuals with a variety of backgrounds to identify evidence-based programs, strategies, approaches, and other research that can be used to improve the care, services, and supports of persons with dementia and their caregivers.

Cross-Cutting Themes

1. Perspectives from persons living with dementia and their caregivers
2. Health disparities
3. Ethics
4. Technology
5. Etiologies

Summit Steering Committee Members

Co-Chairs

Jennifer Wolff, Johns Hopkins University

David Reuben, University of California, Los Angeles

Committee Members

María Aranda, University of Southern California

Susan Beane, Healthfirst

Malaz Boustani, Indiana University School of Medicine

Katie Brandt, Massachusetts General Hospital

Chris Callahan, Indiana University School of Medicine

Elena Fazio, National Institute on Aging

Lori Frank, RAND Corporation

Jason Karlawish, University of Pennsylvania

Ian Kremer, LEAD Coalition

Helen Lamont, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services

Katie Maslow, Gerontological Society of America

Michael Monson, Centene Corporation

Vincent Mor, Brown University

Joanne Pike, Alzheimer's Association

Lonni Schicker, Minnesota State University (Retired)

Robyn Stone, LeadingAge

Sheryl Zimmerman, University of North Carolina



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Transitioning to a Virtual Summit Series

The National Institute on Aging (NIA), in conjunction with the Department of Health and Human Services as part of the National Alzheimer's Project Act (NAPA), planned to host the second National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers on March 24-25, 2020 on the National Institutes of Health main campus in Bethesda, Maryland. The in-person event was canceled per COVID-19 physical distancing guidance. In lieu of the in-person event, the NIA is hosting a 2020 Dementia Care, Caregiving, and Services Research Summit Virtual Meeting Series in Summer 2020. This series will include research presentations, panelist remarks, sharing of the draft research gaps and opportunities, and moderated discussion with live Q&A. The draft research gaps and opportunities, developed by the Summit Steering Committee with input from stakeholder groups and organized into six themes, are intended to identify important potential areas for future research in the fields of dementia care and caregiving.

SUMMIT VIRTUAL MEETINGS SERIES DATES

July 10, 2020, 1:30-4:30 p.m. EDT

July 21, 2020, 1-4:30 p.m. EDT

August 13, 2020, 1:30-5:00 p.m. EDT

The NIA published a Request for Information (RFI) <https://grants.nih.gov/grants/guide/notice-files/NOT-AG-20-035.html> "in June 2020" to provide additional opportunity for stakeholders representing various interested communities, including people living with dementia and care partners, researchers, health care providers, and advocacy organizations, to provide input on the draft research gaps and opportunities developed during the Summit planning process.

Visit the 2020 Summit website for the most up-to-date information:

<https://www.nia.nih.gov/2020-dementia-care-summit>



Recording and Social Media Disclosure

The 2020 Summit Virtual Meeting Series – or the “National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers” – are public meetings. The Summit proceedings are being video/audio recorded and closed captioned. By attending one of these meetings, you grant permission to the National Institutes of Health (NIH) to record the Summit proceedings through these means and to reproduce, copy, or distribute worldwide any such audio and video 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 these sessions. Also, in this public virtual venue, attendees are permitted to capture screenshots/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 control.

Session Themes

1 Theme 1: Impact of Dementia

This theme includes issues related to heterogeneity and trends in the lived experience of dementia, including the clinical impact and trajectory for people living with dementia and their family caregivers across the range of etiologies; the economic impact of dementia for patients, caregivers, payers, public programs, and society; and the effects of dementia, including the impact of health disparities on diverse populations – for example by sex and gender, socioeconomic status, geography, race and ethnicity, language, education, living arrangements, including people living alone or without caregivers.

2 Theme 2: Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers

This theme includes issues related to the organization, financing, and delivery of long-term services and supports (LTSS) in the home and community and in residential settings, such as assisted living and nursing homes. Issues related to the formal care and provider workforce, services provided by community-based organizations, payment and financing, industry, and caregiver needs will be addressed.

3 Theme 3: Services and Supports in Medical Care Settings for Persons with Dementia

This theme includes issues related to the organization, financing, and delivery of medical care across the continuum of health care settings that serve individuals at risk for and living with dementia, including office and home, urgent care, emergency department, hospital inpatient, post-acute care (including skilled nursing facility and home health care), and hospice. Issues related to the care and provider workforce, payment and financing, and industry will be addressed.

2&3 Theme 2 and 3 Integration: The Present and Future of Integrated Long-Term and Medical Care

This theme will address the integration of Themes 2 and 3, including innovations in the organization, financing, and delivery to support integration of medical care and LTSS across the range of settings in which persons with Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) and their caregivers live and receive care.

4 Theme 4: Participation of Persons with Dementia and their Caregivers in Research

This theme will address participation in research. It will consider persons living with dementia and their family caregivers as research participants and as engaged research partners. Topics to be examined include the impact of activated patient communities on study design and outcomes, nomenclature, and strategies for recruitment and retention; optimizing collection of information from a range of sources including persons living with dementia and other informants, technology-based sources, and meta-data; considerations for returning genetic and biomarker information and other study data to participants; and talking about research and research results with persons living with dementia and their family caregivers.

5 Theme 5: Intervention Research, Implementation, and Dissemination

This theme will address methods to improve intervention research relating to dementia care and caregiving that targets individuals, dyads, or organizations and approaches to improve the implementation and dissemination of evidence-based interventions, including strategies to motivate systems change to promote adoption and sustainability.

6 Theme 6: Research Resources, Methods, and Data Infrastructure

This theme includes a focus on methods, data, and processes to facilitate cross-cutting, high-impact research including approaches to intervention research (including pragmatic trials) and observational studies to enable monitoring of progress toward achieving research implementation milestones. Issues include survey infrastructure, ethical frameworks, costs, access to data from electronic health records.

EMERGING TOPICS

This session includes three additional research topics of emerging interest, including emotional functioning in persons living with dementia and their care partners, technological reserve in and use of technology by persons living with dementia, and the implications of preclinical identification of dementia. The presentations will explore the status of and emerging opportunities for research on these topics and future directions as well as implications for persons living with dementia and their care partners.

AGENDAS

[<https://www.nia.nih.gov/dementia-care-summit-virtual-meeting-series-agendas-2020>]

SUMMIT SERIES VIRTUAL MEETING 1

Friday, July 10, 2020

1:30 to 4:30 p.m. Eastern Time

1:30 Welcome and Summit Series Purpose

Speakers: **Jennifer Wolff and David Reuben**

1:40 Setting the Stage – Perspectives

Speakers: **Richard Hodes, Lonni Schicker, Katie Brandt, and Arne Owens**

2:00 Progress Since 2017 Summit

Speaker: **Laura Gitlin**

Impact of Dementia

2:10 Introduction: María Aranda and Ian Kremer

2:15 Research Presentation 1: Population trends of Alzheimer’s disease and related dementias

Speaker: **Rachel Whitmer**

2:25 Research Presentation 2: Disparities in health, services, and interventions for PWD and family caregivers: Evidence and future directions

Speaker: **Ladson Hinton**

2:35 Research Presentation 3: Economic impact of Alzheimer’s disease and value of delaying onset for individuals, caregivers, and society

Speaker: **Julie Zissimopoulos**

2:45 Theme Co-Chairs Present Gaps and Opportunities

2:50 Panelist Perspectives on Gaps and Opportunities

Laura Trejo

Cynthia Huling Hummel

3:00 Moderated Q&A and Discussion

3:15 BREAK

Participation of Persons with Dementia and their Caregivers in Research

3:25 Introduction: Lori Frank and Jason Karlawish

3:30 Research Presentation 1: Reporters, data sources, and outcomes

Speaker: **Lee Jennings**

3:40 Research Presentation 2: Nomenclature: Challenges, issues, and a plan

Speaker: **Ron Petersen**

3:50 Research Presentation 3: PLWD and caregiver research engagement

Speaker: **Tabassum Majid**

3:55 Theme Co-Chairs Present Gaps and Opportunities

4:00 Panelist Perspectives on Gaps and Opportunities

Andrea Gilmore-Bykovskyi

Lonni Schicker

4:10 Moderated Q&A and Discussion

4:25 Closing Remarks

Speakers: **Jennifer Wolff and David Reuben**

4:30 Adjourn

SUMMIT SERIES VIRTUAL MEETING 2

Tuesday, July 21, 2020

1 to 4:30 p.m. Eastern Time

1:00 Welcome and Opening Remarks

Speakers: **Jennifer Wolff and David Reuben**

Services and Supports in Medical Care Settings for Persons with Dementia

1:05 Introduction: Susan Beane and Chris Callahan

1:10 Research Presentation 1: Providing high-quality care in medical care settings

Speaker: **Josh Chodosh**

1:20 Research Presentation 2: Care of persons living with dementia and with multiple chronic conditions

Speaker: **Cynthia Boyd**

1:30 Research Presentation 3: Financing the care of persons living with dementia

Speaker: **Norma Coe**

1:40 Theme Co-Chairs Present Gaps and Opportunities

1:45 Panelist Perspectives on Gaps and Opportunities

Shari Ling

George Hennawi

2:00 Moderated Q&A and Discussion

2:15 BREAK – 10 MINUTES

Long-Term Services and Supports in Home, Community, and Residential Care Settings for Persons with Dementia and their Caregivers

2:25 Introduction: Sheryl Zimmerman and Robyn Stone

2:30 Research Presentation 1: Evidence-based person-centered practices for PLWD and their caregivers: What do we know, where to next?

Speaker: **Kimberly Van Haitsma**

2:40 Research Presentation 2: Understanding the long-term care workforce in a new way

Speaker: **Joanne Spetz**

2:50 Research Presentation 3: Organization and financing of long-term supports and services for persons living with dementia

Speaker: **David Stevenson**

3:00 Theme Co-Chairs Present Gaps and Opportunities:

3:05 Panelist Perspectives on Gaps and Opportunities

Alice Bonner

Laurie Scherrer

3:15 Moderated Q&A and Discussion

3:30 BREAK – 10 MINUTES

Integration: The Present and Future of Integrated Long-Term and Medical Care

3:40 Introduction: Robyn Stone and Chris Callahan

3:45 Research Presentation 1: Building the Case for Integrating LTSS and Medical Care and their Financing for Persons Living with Dementia and their Families

Speaker: **Kerry Branick**

3:55 Research Presentation 2: Signals on Successful Approaches to Integrating LTSS and Medical Care for Persons Living with Dementia

Speaker: **Bruce Leff**

4:05 Theme Co-Chairs Present Gaps and Opportunities

4:10 Moderated Q&A and Discussion

4:25 Closing Remarks

Speakers: **Jennifer Wolff and David Reuben**

4:30 Adjourn

SUMMIT SERIES VIRTUAL MEETING 3

Thursday, August 13, 2020

1:30 to 5:00 p.m. Eastern Time

1:30 Welcome and Opening Remarks

Speakers: **Jennifer Wolff** and **David Reuben**

EMERGING TOPICS

1:35 Presentation 1: Emotional functioning in persons living with dementia and their care partners

Speaker: **Joan Monin**

1:45 Presentation 2: Technological reserve in persons with dementia: The promises and pitfalls of smart systems for health, well-being, and independence

Speaker: **Jared Bengel**

1:55 Presentation 3: Implications of identification at preclinical stages of dementia

Speaker: **Christine Cassel**

2:05 Panelist Perspectives on Gaps and Opportunities

1. **Michael R. Belleville**

2. **Venoreen Browne-Boatswain**

2:15 Moderated Q&A and Discussion

2:30 BREAK

Intervention Research, Implementation, and Dissemination

2:40 Introduction: **Malaz Boustani** and **Michael Monson**

2:45 Research Presentation 1: Developing and disseminating evidence-based care models

Speaker: **Jürgen Unützer**

2:55 Research Presentation 2: Current challenges in implementation science, and implications for improving the care of persons living with dementia

Speaker: **Luci Leykum**

3:05 Research Presentation 3: Learning health systems

Speaker: **Elizabeth McGlynn**

3:15 Theme Co-Chairs Present Gaps and Opportunities

3:20 Discussant: Lisa Onken

3:25 Moderated Q&A and Discussion

3:40 BREAK – 10 MINUTES

Research Resources, Methods, and Data Infrastructure

3:50 Introduction: Vincent Mor and Joanne Pike

3:55 Research Presentation 1: Identification of people living with dementia for population and health care research

Speaker: **Julie Bynum**

4:05 Research Presentation 2: System level research: Pragmatic clinical trials in dementia

Speaker: **Thomas Trivison**

4:15 Research Presentation 3: Consent for research involving persons with dementia: Ethical considerations

Speaker: **David Wendler**

4:25 Theme Co-Chairs Present Gaps and Opportunities

4:30 Panelist Perspectives on Gaps and Opportunities

4. Joe Chung

5. Maggi Miller

6. Craig Thomas

4:40 Moderated Q&A and Discussion

4:55 Closing Remarks

Speakers: **David Reuben and Jennifer Wolff**

5:00 Adjourn

SPEAKER BIOGRAPHIES

BIOGRAPHIES

*2020 Summit Steering Committee Member

†*This person was involved in the Summit planning process and scheduled to speak at the March 2020 in-person event, but due to various circumstances, is unable to participate in the Summit Virtual Meeting Series.*

***María P. Aranda, PhD**, is Associate Professor, University of Southern California (USC) Suzanne Dworak-Peck School of Social Work, and Executive Director, USC Edward R. Roybal Institute on Aging. She leads the Outreach, Recruitment, and Engagement core of the USC Alzheimer's Disease Research Center and the Research Education Core of the USC Alzheimer's Disease Resource Center for Minority Aging Research (RCMAR). Dr. Aranda's research, teaching, and practice interests address the study of psychosocial care of adult and late-life psychiatric disorders including depression and Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD). She is interested in examining racial and ethnic diversity in the delivery of health and mental health services, disparities in health and health care, and testing of psychosocial interventions to alleviate illness burden among persons living with medical and psychiatric illnesses and their family caregivers. Dr. Aranda has served as principal investigator or co-investigator on several studies funded by and/or in collaboration with the National Institute of Mental Health, National Cancer Institute, Patient-Centered Outcomes Research Institute, The John A. Hartford Foundation, The Gerontological Society of America, California Department of Public Health Alzheimer's Disease Programs, the California Community Foundation, National Institute of Rehabilitation and Research, Alzheimer's Association, Health Resources and Services Administration (HRSA), and the Los Angeles County Department of Mental Health. She co-pioneered a state-of-the-art family support program ("El Portal") for low-income, Spanish-speaking families dealing with neurodegenerative disorders, which is a national model for family caregiving in hard-to-reach communities. Dr. Aranda has served on several consensus committees sponsored by the National Academy of Medicine on the geriatric workforce in mental health and substance use service sectors, family caregiving to older adults with functional limitations, financial capacity determination and functional assessments among Social Security beneficiaries. She is a licensed psychotherapist with extensive experience providing bilingual and bicultural mental health services to middle-aged and older adults and their families.

***Susan Beane, MD**, joined Healthfirst in 2009, bringing with her extensive professional experience in managed care. As Vice President and Executive Medical Director at Healthfirst, Dr. Beane focuses on care management and clinical provider partnerships, programs especially designed to improve the delivery of vital, and evidence-based health care to our members. Dr. Beane is a strong proponent of collaborating with and engaging providers to improve health outcomes. Dr. Beane leads Healthfirst in collaborating with major health care delivery systems and local and national policy experts on the design, implementation, and dissemination of innovative, outcomes-focused models of care. Her research contributions span health of caregivers, obesity, and maternal health. Prior to joining Healthfirst, Dr. Beane served as Chief Medical Officer for Affinity Health Plan for 5 years, during which time she helped Affinity's plan become a top performer in quality and member satisfaction. Before that, she worked at AmeriChoice and HIP USA as Medical Director. Dr. Beane is a graduate of Princeton University and Columbia University College of Physicians and Surgeons.

Michael R. Belleville retired at the age of 54 after being diagnosed with Lewy Body dementia. Mike was a telecommunications technician for nearly 20 years and served in the Rhode Island Air National Guard for 12 years. After realizing that he could still contribute in a meaningful way, Mike became an advocate for those living with dementia. He was a member of the Alzheimer's Association national Early Stage Advisory Group in 2016.

Mike's main advocacy focus now is working with the Dementia Action Alliance to help others and to work to reduce the stigmas associated with dementia. Mike's favorite quote is from Jackie Robinson: "A life is not important except for the impact it has on other lives." In Mike's opinion, no organization personifies that quote better than the Dementia Action Alliance.

Jared F. Benge, PhD, is clinical neuropsychologist in the Department of Neurology and Plummer Movement Disorders Center at Baylor Scott and White in Temple, TX. Dr. Benge serves as the director of neurology research, training director for the neuropsychology fellowship program and associate program director for neurology resident research. He is a clinical assistant professor at Texas A&M College of Medicine and an adjunct assistant professor at Baylor University. Clinically, he performs cognitive assessments of individuals with known or suspected neurodegenerative diseases. His research interests have focused on issues surrounding assessment and patient-centered outcomes in neurodegenerative diseases with work funded by the Alzheimer's Association and Parkinson's Diseases Foundation. He recently has served as site principal investigator for an National Institute on Aging (NIA)-funded randomized clinical trial (RCT) evaluating smartphone interventions for aiding prospective memory in those with mild cognitive impairment or dementia. He earned his doctorate degree from the University of Houston with post-doctoral training in neuropsychology at the Michael E. DeBakey Veterans Affairs (VA) Medical Center.

Alice Bonner, PhD, RN, has been a geriatric nurse practitioner caring for older adults and their families for over 30 years. She is currently Adjunct Faculty and Director of Strategic Partnerships for the CAPABLE Program at the Johns Hopkins University School of Nursing and Senior Advisor for Aging at the Institute for Healthcare Improvement (IHI). From 2015-2019, she served as Secretary of the Executive Office of Elder Affairs for the Commonwealth of Massachusetts. From 2011 to 2013, Dr. Bonner served as Director of the Division of Nursing Homes in the Centers for Medicare & Medicaid Services (CMS) in Baltimore, MD. From 2009-2011, she was the Director of the Bureau of Health Care Safety and Quality, at the Massachusetts Department of Public Health. Dr. Bonner has also been an Affiliate Associate Professor in the School of Nursing at Northeastern University. Her research interests include policy development to promote quality and safety in health systems and community-based settings, elder abuse, falls prevention, improving dementia care and reducing unnecessary antipsychotic medication use, and improving care transitions.

***Malaz Boustani**, MD, MPH, is a geriatrician, a neuroscientist, and an implementation scientist with extensive experience in developing, evaluating, implementing, and disseminating health care innovations with a main focus on brain health. He is the Founding Director of the Sandra Eskenazi Center for Brain Care Innovation and the Chief Innovation and Implementation Officer for Indiana University Center for Health Innovation and Implementation Science (www.hii.iu.edu). Over the past decade, Dr. Boustani has built a clinical laboratory of more than 2,000 ambulatory practices serving at least 10 million lives within five Midwestern States (Illinois, Indiana, Michigan, Ohio, and Kentucky). He used the clinical laboratory to lead the execution of numerous clinical research studies funded by the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), and CMS totaling more than \$100 million. He has more than 160 peer-reviewed publications.

Cynthia Boyd, MD, MPH, is Professor of Medicine, Epidemiology, and Health Policy and Management at Johns Hopkins University with her primary home in the Division of Geriatric Medicine and Gerontology. She is a practicing primary care physician at Johns Hopkins Bayview Medical Center and is a clinical researcher who has devoted her career to improving the health and health care of older adults with multiple chronic conditions, including dementia. Her research has been funded by the National Institute on Aging, the Patient Centered Outcomes Research Institute, the Agency for Healthcare Research and Quality, and private foundations. Her research has focused on improving guidelines, health and health care for older adults with multiple chronic conditions and dementia and their loved ones, through both observational and interventional research. Dr. Boyd is currently co-leading and leading efforts to study the balance of benefits and harms of medications for this important population, including evaluating the role of “deprescribing” medicines that are harmful or not beneficial in order to improve the well-being of older adults. Dr. Elizabeth Bayliss and Dr. Boyd are co-leading an evaluation of a patient and family centered intervention in primary care to optimize medications for older adults with cognitive impairment and other chronic conditions. Together with Dr. Michael Steinman, from UCSF, Dr. Boyd is co-leading the NIA-funded U.S. Deprescribing Research Network.

***Katie Brandt, MM**, is the Director of Caregiver Support Services and Public Relations for the Frontotemporal Disorders (FTD) Unit at Massachusetts General Hospital and Co-Chair of the National Alzheimer’s Project Act (NAPA) Advisory Council on Alzheimer’s Research, Care, and Services. Ms. Brandt is certified as an Alzheimer’s Care Manager in Massachusetts and as a trainer for the Habilitation Therapy model of care for persons living with dementia. She is a coordinator for advocacy, education, support, and community events for patients, caregivers, and families living with AD, FTD, and related atypical and young-onset dementias. Ms. Brandt is an Alzheimer’s caregiver for her father, Tom, and a former FTD caregiver for her late husband, Michael. Her experiences of love and loss have inspired her role as a global advocate, educator and fundraiser for AD/ADRD research, with determination that the cure of tomorrow is not so far from the care of today.

Kerry Branick, MPH, is the deputy director of the Models, Demonstrations, and Analysis Group in the Medicare-Medicaid Coordination Office (MMCO) at CMS. She leads work with the state of California on their capitated model demonstration under the Medicare-Medicare Financial Alignment Initiative. Prior to joining MMCO in 2011, she worked at the Office of the National Coordinator for Health Information Technology and HRSA on supporting states and providers implementing health information technology and information exchange. Ms. Branick has a Master of Public Health with a focus on health policy and emergency management from The George Washington University.

Venoreen Browne-Boatswain is a leader with over 35 years in higher education leadership. Ms. Browne-Boatswain has led university teams in Student Affairs, Diversity, and Multiculturalism. She is an active community leader, a member of Toastmasters, and consulting mediator for various companies for more than 2 decades. Ms. Browne-Boatswain is passionate about raising awareness of dementia to communities of color, supporting loved ones of dementia patients in diverse communities, and informing health care practitioners about the experiences of families of color who have received dementia care. Venoreen educational background includes a M.Ed., Student Personnel Services, and a bachelor’s degree in sociology.

†**Mary Butler**, PhD, Associate Professor in the University of Minnesota School of Public Health Division of Health Policy and Management, trained in health services research with special emphasis on outcomes research and health behaviors in alternative medicine. Her areas of interest include scientific evidence standards, research design and systematic review methodology, evidence-based or evidence-informed health care, and complexity science in health and health care. Dr. Butler is co-director of the Minnesota Evidence-based Practice Center (EPC) and has led or overseen review projects over the last 13 years on a wide range of topics, specializing in complex patients and complex interventions.

Julie P. W. Bynum, MD, MPH, is the Margaret Terpenning Professor of Internal Medicine at the University of Michigan where she is also Research Professor in the Institute of Gerontology, Associate Director for Health Policy and Research at the Geriatrics Center, and a member of the Institute for Health Policy and Innovation. Bynum received her medical and public health degrees from Johns Hopkins University, completed her internal medicine residency at Dartmouth, and completed her specialty training in Geriatric Medicine at Johns Hopkins. She then joined the faculty at Dartmouth Medical School where she was funded as a Robert Wood Johnson Physician Faculty Scholar and an NIA Beeson Scholar to study quality and efficiency of health care delivery to high-risk elderly. In addition, she has been a Health and Aging Policy Fellow and was a member of the National Academy of Medicine Committee that published "Vital Signs: Core Metrics for Health and Health Care Progress". She is a current member of the National Academies of Science, Engineering, and Medicine (NASEM) Forum on Aging, Disability, and Independence. In her research, Dr. Bynum has led interdisciplinary teams of investigators (clinicians, economists, sociologists, and data scientists) who apply observational study methods to questions about performance of the health system and the complex drivers of quality and costs for older adults, especially those nearing the end of life or with Alzheimer's disease. She has conducted multiple studies of medical care of people with AD/ADRD and as a result was the guest editor of a special edition of *Health Affairs* dedicated to policy issues related to Alzheimer's disease. Her current NIH-funded portfolio includes studies of early diagnosis, outcomes of new surgery approaches among people with dementia, outcomes after reduction of anti-psychotic exposure, methods to identify people with AD/ADRD using contemporary health data sources for pragmatic clinical trials.

***Christopher M. Callahan**, MD, MACP, is a Professor of Medicine at the Indiana University School of Medicine and the Chief Research and Development Officer at Eskenazi Health in Indianapolis, Indiana. Eskenazi Health is one of the nation's largest safety net health systems. 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 a fellowship in Health Services Research at the Indiana University School of Medicine in 1991. He served as the Director of the Indiana University Center for Aging Research for 21 years, from 1997-2018. Board-certified in geriatric medicine, his clinical practice at Eskenazi Health focuses on the care of older adults with depression and dementia. He is also a Scientist in the Regenstrief Institute. Dr. Callahan and his colleagues study interventions and new models of care to improve the care of older adults in primary care. This work includes clinical trials exploring new models of care for persons with dementia and depression. These models increasingly focus on the integration of family, community, and medical services. He has mentored dozens of junior faculty seeking to pursue careers in academic geriatric medicine. He received the Midcareer Research Mentorship Award from the Society of General Internal Medicine in 2006 and the Edward Henderson Award from the American Geriatrics Society in 2016. 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).

Christine K. Cassel, MD, is Senior Advisor for Strategy and Policy in the Department of Medicine at the University of California, San Francisco (UCSF). Her current work is focused on bioethics related to science and technology frontiers in health care. She is a national leader in geriatrics, bioethics, and quality of care. From 2016-2018, Dr. Cassel was Planning Dean for the new Kaiser Permanente School of Medicine. From 2013-2016 she was the President and CEO of the National Quality Forum and prior to that served as president and CEO of the American Board of Internal Medicine and the ABIM Foundation. Dr. Cassel was one of 20 scientists in the Obama administration President's Council of Advisors on Science and Technology (PCAST). She was the co-chair of PCAST reports on health information technology, scientific innovation in drug development and evaluation, systems engineering in health care, technology to foster independence and quality of life in an aging population, and safe drinking water systems. She is an internist and geriatrician, as well as one of the first clinicians trained in geriatrics and in bioethics. Her academic leadership roles included Dean of the OHSU SOM, chair of the Department of Geriatrics at Mount Sinai, and Chief of General Internal Medicine at the University of Chicago. A member of NASEM since 1992, she co-authored the landmark reports "To Err is Human" and "Crossing the Quality Chasm" and became a national leader in quality of care. She was the first woman President of the American College of Physicians and has received numerous honorary degrees, authored more than 200 articles, and authored or edited 11 books, including one of the leading textbooks in geriatric medicine.

†Molly Checksfield, MPA, is a program officer with the Board on Behavioral, Cognitive, and Sensory Sciences (BBCSS) at NASEM in Washington, D.C. She serves as study director for the decadal survey to provide the NIA with a research agenda for the next decade in the behavioral and social sciences as it relates to AD/ADRD. She also led a workshop on Mobile Technology for Adaptive Aging in December 2019 and currently serves as North American Regional Coordinator of the World Young Leaders in Dementia (WYLD) network. Prior to joining BBCSS, she worked as a program manager for the National Active and Retired Federal Employees Association. She served as a member of the Board of Directors and Chair of the Junior Board for the National Capital Area Chapter of the Alzheimer's Association. Additionally, she was the Legislative Director for Social Security Works in Washington, D.C., and worked for a Senator who serves on the Committee on Aging. She received a Master of Public Administration and an Advanced Certificate in Health Services Management and Policy from the Maxwell School of Citizenship and Public Affairs at Syracuse University and has a B.S. in Human Development and Family Studies from the University of Vermont.

Joshua Chodosh, MD, MSHS, holds the inaugural endowed Michael L. Freedman Professor of Geriatric Research Chair in the Division of Geriatric Medicine and Palliative Care in the Department of Medicine at the New York University (NYU) Grossman School of Medicine. He is Professor of Medicine and Population Health and a clinical geriatrician, caring for patients at NYU Langone Health and the VA Harbor Healthcare System in Manhattan, and is the founding Director of the Freedman Center on Aging, Technology, and Cognitive Health (CATCH). He also co-founded and co-directs the NYU Aging Incubator, a University-wide network of researchers, clinicians, and educators who are dedicated to aging-related investigations, awareness-raising, and problem solving. Dr. Chodosh is currently principal investigator (PI) or multi-PI of multiple NIA, National Institute of Nursing Research (NINR), and VA clinical implementation trials, leads the Outreach, Recruitment, and Engagement Core of the NYU Alzheimer's Disease Research Center, and has published widely on models of care for persons living with dementia and their family caregivers. Dr. Chodosh has several junior faculty, fellow, and post-doctoral mentees who focus on the

intersection between AD/ADRD, multiple chronic conditions, and race/ethnicity. He has also established the NYU Hearing Healthcare Research Collaborative, which focuses on age-related hearing loss and patient-physician communication. Most recently, Dr. Chodosh and colleagues launched an NIA-supported R24 award focused on building best-practices and innovative approaches for recruitment and retention of older age participants from underrepresented groups with a particular focus on AD/ADRD. He has held a number of leadership roles focused on health care policy impacting the quality of care for patients with chronic disease, particularly those with dementia. Prior to moving to NYU in 2015, Dr. Chodosh served as Chair of the State of California Alzheimer's and related Dementias Advisory Committee and co-chaired a statewide effort leading to the California State Plan for Alzheimer's disease.

Joseph Chung is co-founder and CEO of Kinto, a care management platform for family caregivers looking after loved ones with AD/ADRD. He is also co-founder and Managing Director of Redstar Ventures, an innovative venture foundry developing a series of new companies through a top-down, market driven process. Prior to Kinto and Redstar he was Chairman and CEO of Allurent and co-founder, Chairman and CTO of Art Technology Group (NASDAQ: ARTG). Along with Jeet Singh, he led the growth of ATG from a two-person consultancy to a publicly traded, global enterprise software company with over 1,200 employees and annual revenues exceeding \$160 million. ATG was acquired by Oracle in 2010 for \$1B. Mr. Chung holds BS and MS degrees in computer science from the Massachusetts Institute of Technology (MIT), and he conducted his graduate work at the MIT Media Lab under professors Tod Machover and Marvin Minsky. Mr. Chung serves on the Board of Directors of Eastern Bank, the nation's oldest and largest mutual bank, and is a Venture Partner at the Media Lab's E14 Fund.

Norma B. Coe, PhD, is an Associate Professor of Medical Ethics and Health Policy at the Perelman School of Medicine at the University of Pennsylvania (Penn), and the Director of the Policy and Economics of Disability, Aging, and Long-Term Care (PEDAL) lab. Her research interests are in health economics and public finance. Her research focuses on identifying causal effects of policies that directly and indirectly impact health, human behavior, health care access, and health care utilization. In her research, Dr. Coe merges the rigor of economic thinking and empirical analysis with the practical health services skills of measurement and knowledge of the health policy context to answer pressing questions for policymakers and other stakeholders on how we can improve aging in America. Dr. Coe currently has three R01 awards funded by the NIA, focusing on long-term care and end-of-life care, with an emphasis on those with AD/ADRD. Prior to joining Penn, she was an Assistant Professor in Health Services at the University of Washington and the Associate Director of Research at the Boston College Center for Retirement Research. She received her PhD in Economics from MIT and BA in Economics from the College of William and Mary.

†Chaneë Fabius, PhD, is an assistant professor at the Johns Hopkins University Bloomberg School of Public Health. She is a gerontologist and health services researcher with an interdisciplinary background consisting of training in gerontology, human development and family studies, and public health. Her research informs aging and disability policies to reduce health care disparities and improve health equity for older adults and people with disabilities using long-term services and supports (LTSS). Her interests are informed by applied clinical care management experience, where she helped older adults remain at home and delay the need for nursing home care. She is interested in: (1) better understanding networks of care (e.g. LTSS such as home and community-based services and family support) used by older people and how those may vary by race and socioeconomic status, (2) examining the effect of community-based LTSS utilization on quality of life and health service utilization across diverse groups of older adults, and (3) strengthening the direct care workforce that provides services and supports to vulnerable older adults, such as those with complex conditions like dementia. She completed a 2-year AHRQ-funded T32 Postdoctoral Fellowship in the Center for Gerontology and Healthcare Research at the Brown School of Public Health in 2018. She earned her PhD in Human Development and Family Studies from the University of Connecticut in 2016.

***Elena Fazio**, PhD, is a Health Scientist Administrator in the Division of Behavioral and Social Research at the NIA. She works primarily on projects supporting the goals of the National Alzheimer's Plan of Action (NAPA), including serving as the program official for grants related to long-term supports and services for older adults and the demography of aging. Dr. Fazio previously worked for the U.S. Administration for Community Living (ACL), where she led a variety of projects focused on program performance, national data collection (survey data and administrative data), and research on services and supports provided to older adults and persons with disabilities. She initiated a redesign of the National Survey of Older Americans Act Participants and managed improvements in data collection and reporting for ACL's State Program Reports. Dr. Fazio has planned workshops, written issue briefs, and led task forces on topics such as the workforce for community care, chronic disease self-management, end-of-life care, dementia care interventions, and improving outcomes for carers and persons living with AD/ADRD. Before joining NIA and ACL, she was staff director for the Federal Interagency Forum on Aging-related Statistics. As a post-doctoral fellow, she served as project director for the NIA-funded Aging, Stress, and Health program. Dr. Fazio's PhD in Sociology was awarded by the University of Maryland. Her published research deals with stress, mental and physical health, and health disparities in late life.

***Lori Frank**, PhD, is a Senior Scientist with the RAND Corporation. Her current work is focused on methods for incorporating the consumer perspective into health outcomes research, clinical care, and health care valuation. Prior to joining RAND, she completed her Health and Aging Policy Fellowship through the American Political Science Association Congressional Fellowship Program with a placement at the NIA. She founded and served as Program Director of the Evaluation and Analysis Program at the Patient-Centered Outcomes Research Institute (PCORI), establishing a research program to examine stakeholder engagement, along with survey research and portfolio analysis functions. Prior to joining PCORI she served as Executive Director and Senior Research Leader of the Center for Health Outcomes Research, MEDTAP International/United BioSource Corporation, where she managed the scientific and financial performance of the Center, overseeing international operations. Dr. Frank initiated and served as principal investigator of the Cognition Initiative with the Critical Path Institute PRO Consortium. She is currently President of the International Society for Quality of Life Research (ISOQOL), serves on the Board of the Personalized Medicine Coalition, and a member of the Medical, Scientific, and Memory Screening Advisory Board of the Alzheimer's Foundation of America. Her career has focused on patient-reported outcomes measure development and assessment and the psychological, ethical, and legal aspects of memory screening and medical treatment decision-making. She has held research and teaching positions with Georgetown University Department of Psychiatry, the NIA, Medimmune LLC/AstraZeneca, and the VA. She completed postdoctoral training in Mental Health Services Research with the VA Health Services Research and Development program and Department of Psychiatry, University of Arkansas School for Medical Sciences. Her PhD is in Human Development/Gerontology from the Pennsylvania State University and her MA is in Biopsychology from the Johns Hopkins University.

Andrea Gilmore-Bykovskiy, PhD, is an Assistant Professor at the University of Wisconsin-Madison, and a co-investigator in the Wisconsin Alzheimer's Disease Research Center Care Research Core. A 2018 recipient of an NIA Paul B. Beeson Emerging Leaders Career Development Award, Dr. Gilmore-Bykovskiy leads a program of research focused on promoting effective and equitable care and research for persons living with, and at risk for AD/ADRD. Much of her research has focused on addressing challenging points in the care continuum, such as acute illness and transitions in care, and on care for underserved and vulnerable populations. Major areas of foci in her program include treatment and utilization disparities, care delivery and caregiver support, and issues in research ethics and equity specific to Alzheimer's and dementia. Dr. Gilmore-Bykovskiy's original research has contributed foundational knowledge to our understanding of caregiver approaches that precipitate or mitigate non-cognitive symptoms in dementia, dementia-specific transitional care needs, and issues in the application of narrative electronic health record data to identify persons with potential dementia. In much of her research, she and her team have partnered directly with people with dementia and caregivers to fully integrate their perspectives into the research process and results. Dr. Gilmore-Bykovskiy has served on regional and national initiatives to address management of

symptoms experienced by persons living with cognitive impairment, most recently serving on the Veterans Health Administration Inpatient Care for Veterans with Complex Cognitive, Mental Health and Medical Needs Task Force. Dr. Gilmore-Bykovskyi's research has been funded by the American Nurses Foundation, the National Hartford Centers of Gerontological Nursing Excellence, the NIA, and the National Institute on Minority Health and Health Disparities (NIMHD).

Laura N. Gitlin, PhD, FGSA, FAAN, is an applied research sociologist and the Distinguished Professor and Dean of the College of Nursing and Health Professions at Drexel University. She is also an adjunct faculty of Johns Hopkins School of Nursing. Dr. Gitlin is nationally and internationally recognized for her research on developing, evaluating, and implementing novel home- and community-based interventions to improve quality of life of older adults with functional challenges and persons living with dementia and their care partners. She is a well-funded researcher, having received continuous research and training grant dollars from federal agencies and private foundations for over 35 years. In her research, she applies a social ecological perspective and person-family-directed approach to examine, intervene, and support individuals in their living environments. Her efforts involve collaborating with community organizations, health and human service professionals, and other stakeholders to maximize the relevance and impact of such interventions. She is also involved in translating, disseminating, and implementing proven programs developed with her team for delivery in diverse practice settings globally and in the U.S. Dr. Gitlin is the recipient of numerous awards, has authored more than 300 scientific publications and has co-authored seven books.

George Hennawi, MD, is the Director of Geriatrics at MedStar Good Samaritan Hospital and medical director of the Center for Successful Aging. He is interim medical director of the MedStar House Calls Program and an assistant clinical professor at the University of Maryland School of Medicine. Dr. Hennawi specializes in providing team-based, person-centered care to vulnerable elders. He has received numerous honors, including recognition by Physician Practice Connections, Patient-Centered Medical Home, Bridges to Excellence in Diabetes and Bridges to Excellence Medical Home program. He was ranked as "Top Doc" in Geriatrics by Baltimore Magazine each year from 2013 until present. Under Dr. Hennawi's leadership, the Center for Successful Aging was selected to participate in the Age Friendly Health Systems Initiative sponsored by the IHI and the John A. Hartford Foundation, the NCQA Person-Driven Outcomes study, and HRSA's Geriatric Workforce Enhancement Program. An active member of the MedStar community, Dr. Hennawi serves on the Primary Care Clinical Council, Medical Executive Committee, Ethics Committee and CME Committee. He is the lead physician for the Nurses Improving Care for Health System Elders (NICHE) program. He is currently the president of the medical staff at MedStar Good Samaritan Hospital. Dr. Hennawi is board certified in Internal Medicine, Geriatrics, Hospice and Palliative Care and a certified medical director. His medical degree is from University of Damascus (Syria). He completed an internship and residency in Internal Medicine at MedStar Union Memorial Hospital and his Geriatric Medicine fellowship at the University of Virginia, Charlottesville.

Ladson Hinton, MD, is a professor, geriatric psychiatrist, clinical and services researcher, and social scientist in the Department of Psychiatry and Behavioral Sciences at University of California, Davis (UC Davis). Over the past two decades, he has conducted interdisciplinary research using both qualitative and quantitative methods to understand the social and cultural dimensions of caregiving for people living with AD/ADRD. He has applied this knowledge to develop innovative and culturally appropriate intervention approaches to advance care and services for underserved populations in the US and globally (Vietnam and Thailand). Dr. Hinton was a member (2014-2016) of the NASEM ad hoc Committee on Family Caregiving (Report title: Families Caring for an Aging America), PI (2012-19) of the NIA-funded RCMAR, and Director (2005-2017) of the Outreach and Recruitment Core for the UC Davis Alzheimer's Disease Research Center. He is co-assistant director for research of the Family Caregiving Institute in the School of Nursing. He served as cross-cutting chair for diversity at the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers.

Richard J. Hodes, MD, is the Director of the NIA at the NIH. Dr. Hodes, a leading researcher in the field of immunology, was named to head the NIA in 1993. Under Dr. Hodes' stewardship, the NIA budget has grown to \$3 billion, reflecting increased public interest in aging as America and the world grow older. Dr. Hodes has devoted his tenure to the development of a strong, diverse, and balanced research program, focusing on the genetics and biology of aging, basic and clinical studies aimed at reducing disease and disability, including AD/ADRD; age-related cognitive change; and investigations of the behavioral and social aspects of aging. Cutting-edge research conducted and supported by the NIA, often in collaboration across institutes at the NIH, has helped to revolutionize the way we think about these conditions. Dr. Hodes' research laboratory in the National Cancer Institute (NCI) focuses on the cellular and molecular mechanisms that regulate the immune response. A graduate of Yale University, Dr. Hodes received his MD from Harvard Medical School. He is a Diplomate of the American Board of Internal Medicine, a member of The Dana Alliance for Brain Initiatives, a Fellow of the American Association for the Advancement of Science, and a member of the National Academy of Medicine at NASEM.

Cynthia Huling Hummel, BS, DMin, MDiv, of Elmira, New York served in parish ministry for 15 years prior to her diagnosis of early stage Alzheimer's disease. She received her BS from Rutgers College, her MDiv from New Brunswick Theological Seminary, and her DMin from McCormick Theological Seminary. Rev. Dr. Huling Hummel is a fierce Alzheimer's advocate and has become a voice for those living with the disease locally, nationally, and internationally. She served as a National Early-Stage Advisor for the Alzheimer's Association and recently completed a 2-year term on the NAPA Advisory Council on Alzheimer's Research, Care, and Services representing the 5.8 million Americans living with AD/ADRD. She is passionate about Alzheimer's research and is in her 10th year of the Alzheimer's Disease Neuroimaging Initiative (ADNI) study. She is serving as a member of the Research Participant Advisory Board of the ACTC Consortium. Rev. Dr. Huling Hummel serves on the Dementia Action Alliance Advisory Board and the NASEM Alzheimer's Decadal Survey. This is her third NIH Research Summit. Rev. Dr. Huling Hummel sings in the band *Country Magic* and in 2016 and was inducted into the New York State Country Music Hall of Honor. She also sings in her community choir and leads the *Faithful Friends Singers* for those living with dementia and care partners. She enrolled at Elmira College in 2011 and is auditing her 39th class. Rev. Dr. Huling Hummel is an artist and an author. Her book, *UnMasking Alzheimer's*, is a compendium of stories and photos of the 36 masks that she created. Ten of her Alzheimer's masks were displayed at the National Gallery of Art in Stockholm during the 2019 Dementia X Conference. Rev. Dr. Huling Hummel loves to travel, kayak, swim, and enjoys serving as a substitute preacher. Her mantra is "Don't focus on what you can't do. Focus on how you can still make a difference."

Lee A. Jennings, MD, MSHS, Chief and Assistant Professor, Reynolds Section of Geriatric Medicine at the University of Oklahoma Health Sciences Center, is a board-certified geriatrician and health services researcher whose work focuses on improving models of care delivery for dementia, aligning care received with patient health goals, and improving the competency of health professions students to provide high quality geriatric care. She is the principal investigator for three statewide grants funded by HRSA, ACL, and the Reynolds Foundation focused on geriatric health care workforce development and community health education for older Oklahomans and their family caregivers. She is a co-investigator on research funded by PCORI, NIA, and the John A. Hartford Foundation and co-chair of the Women in Geriatrics Section for the American Geriatrics Society. Clinically, she specializes in comprehensive geriatric assessment and cognitive evaluation and sees patients at the OU Physicians Senior Health Clinic and the Oklahoma City VA Health System.

***Jason Karlawish**, PhD, is a Professor of Medicine, Medical Ethics and Health Policy, and Neurology at Penn and cares for patients at the Penn Memory Center, which he co-directs. His research focuses on issues at the intersections of bioethics, aging, and the neurosciences. He leads the Penn Program for Precision Medicine for the Brain (P3MB). P3MB developed standards for Alzheimer's disease biomarker disclosure and investigates the clinical impacts of this knowledge on persons and their families. He has investigated the psychological and ethical implications of biomarker-based Alzheimer's disease diagnostics and treatments, informed consent, quality of life, research and treatment decision making, stigma, and voting by persons with cognitive impairment and residents of long-term care facilities. His essays on aging, ethics, and Alzheimer's disease have appeared in Forbes.com, KevinMD, the New York Times, the Philadelphia Inquirer, and STAT news. He is currently writing *The Disease of the Century*, an account of how Alzheimer's disease became a crisis and the steps needed to address it (St Martin's Press). Dr. Karlawish has disseminated his research in leading textbooks of medicine and bioethics, testimony to the Senate Select Committee on Aging, and Committee on Finance and the Department of Health and Human Services Subcommittee on the Inclusion of Individuals with Impaired Decision-making in Research, and collaborations with the Alzheimer's Disease Cooperative Study, the Alzheimer's Association, American Bar Association's Commission on Law and Aging, AARP's Global Council on Brain Health, the Department of Housing and Urban Development, the National Academy of Medicine (he served on the committee to address the public health challenges of cognitive aging), the State of Vermont, the U.S. Election Assistance Commission, and the U.S. Government Accountability Office. He studied medicine at Northwestern University and trained in internal medicine and geriatric medicine at Johns Hopkins University and the University of Chicago.

†Michelle Kraus is a Senior Executive with more than 24 years of experience in health care services. Michelle is currently the Executive Director at Ingleside at King Farm (IKF), a non-for-profit, Continuing Care Retirement Community (CCRC), that offers senior living housing for independent living, assisted living, memory support assisted living, and skilled nursing residents in Rockville, Maryland. From 2015-2018, Ms. Kraus served as Vice President of Operations for Vero Health Management overseeing four long-term care facilities in Massachusetts and Georgia. Most of her leadership and operations experiences derived from her 18-year tenure as Senior Administrator at Arcola Health and Rehabilitation Center in Silver Spring, Maryland. She consistently achieved operational excellence in areas of Quality Assurance Performance Improvement, CMS Five-Star Quality Ratings, CARF Accreditation, Joint Commission Accreditations, annual federal and state regulatory survey results, financial profitability, employee stability, and customer satisfaction. Ms. Kraus has a proven ability to formulate performance-based business and utilize her analytical talents to yield compelling results. Her ability to motivate and lead others stems from a passion to educate, mentor, and empower individuals professionally. Ms. Kraus is a graduate of the University of Maryland, College Park with a Master of Health Services Administration from The George Washington University. She has held an active NHA license since 1997. She is a recipient of the 2008 Administrator of the Year Award from the Health Facilities Association of Maryland. She led Arcola Health and Rehabilitation Center in achieving the 2012 American Health Care Association (ACHA) Bronze Award-Commitment to Quality. In 2009, Michelle was appointed by the Governor to the Maryland State Board of Examiners for Nursing Home Administrators and was selected to act as the Board Chairperson in 2016 while serving her last year.

***Ian N. Kremer**, JD, serves on the steering committee for the 2020 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers and co-chairs Theme 1: Impact of Dementia. Mr. Kremer also served on the 2017 Summit steering committee. He has worked on federal, state, and local dementia policy since 1996. Kremer is Executive Director of the LEAD Coalition (Leaders Engaged on Alzheimer's Disease: <http://www.leadcoalition.org>) uniting 100 member organizations and 100 allied organizations. The LEAD Coalition accelerates transformational progress in care and support to enrich the quality of life of those with dementia and their caregivers, detection and diagnosis, and research leading to prevention, effective treatment, and cures. Since 2012, the LEAD Coalition has helped to secure historic funding increases for NIH, advocated to protect dementia-relevant components of the Patient Protection and Affordable Care Act and the Medicaid program,

collaboratively led efforts to expand family caregiver roles in medical product development, and worked with a dozen federal agencies to clarify regulatory pathways, combat elder abuse, and improve cognitive impairment detection and diagnosis, clinical care, and access to home- and community-based services. Currently, Mr. Kremer serves on the Public Policy and Aging Report editorial board, and on steering and advisory committees for the NIA-funded IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory, the UCLA Dementia Care Study, the Alzheimer's Disease Patient and Caregiver Engagement (AD PACE) initiative, the Dementia Friendly America initiative, the Brain Health Partnership, and Dementia Alliance International. Previously, **Mr. Kremer** has served on steering and advisory committees for the Centers for Disease Control and Prevention (CDC) Healthy Brain Initiative Roadmap, the Gerontological Society of America Workgroup on Cognitive Impairment Detection and Earlier Diagnosis, and the PCORI Dementia Research Methods project. He holds degrees from Washington University in Saint Louis and the University of Michigan School of Law.

***Helen Lamont**, PhD, is a senior analyst in the Office of the Disability, Aging, and Long-Term Care Policy in the Office of the Assistant Secretary for Planning and Evaluation (ASPE). Dr. Lamont leads the implementation of the National Alzheimer's Project Act (NAPA), managing the Advisory Council on Alzheimer's Research, Care, and Services and writing the annual update to the National Plan to Address Alzheimer's Disease. In this role, she works closely with partners across the U.S. Department of Health and Human Services (HHS) and the federal government to carry out the National Plan and leverage the capabilities of the individual agencies through interagency collaborations. Dr. Lamont leads the ASPE portfolio of policy research on dementia including work on identifying dementia in surveys and Medicare claims, functional trajectories of people with advanced dementia, self-neglect, and family caregiving. She also conducts research on disability data, elder justice, and health promotion and prevention for older adults. Dr. Lamont has a BS in Human Development from Duke University and a PhD in Aging Studies from the University of South Florida.

Bruce Leff, MD, is Professor of Medicine at the Johns Hopkins University School of Medicine in the Division of Geriatric Medicine and Gerontology. He holds joint appointments at the Johns Hopkins University Bloomberg School of Public Health and the Johns Hopkins School of Nursing. He is the Director of the Center for Transformative Geriatric Research at Johns Hopkins. His principal areas of health services research relate to the development, evaluation, and dissemination of innovative models of health service delivery for older adults including Hospital at Home, Guided Care, home-based primary care, and others. His research interests also include issues related to the care of people with multiple chronic conditions, the development of quality indicators for home-based medical care and quality improvement, guideline development and case-mix issues. He is the author of more than 200 peer-reviewed publications and book chapters. Dr. Leff has a strong interest in health policy and is a past Health and Aging Policy Fellow and has served on multiple National Quality Forum and CMS Technical Expert Panels. Dr. Leff cares for patients in the acute, ambulatory, and home settings and is an award-winning teacher and mentor. He currently serves as the Chair of the Geriatric Medicine Board of the American Board of Internal Medicine (ABIM) and is Chair-elect of the ABIM Council. He is past President and current board member of the American Academy of Home Care Physicians, and past member of the Board of Regents of the American College of Physicians. He serves on the editorial board of the *Annals of Internal Medicine* and is a Care Redesign Thought Leader for the *New England Journal of Medicine Catalyst*.

Luci K. Leykum, MD, is a General Internist and health services researcher in the South Texas Veterans Health Care System and Professor of Medicine at Dell Medical School at the University of Texas at Austin. She is the principal investigator and center lead for the Elizabeth Dole Center of Excellence for Veteran and Caregiver Research and also serves as Associate Chair for Clinical Innovation for the Department of Medicine at Dell Medical School. Dr. Leykum's research has used the framework of complexity science to understand and improve clinical systems. Specifically, she has studied interdependencies within clinical systems, focusing on how clinicians, patients, and families come to make sense of what is happening and how they act based on those shared understandings. Her current work aims to improve patient outcomes through advancing the ability of clinicians, patients, and families to co-create care plans that are most appropriate for each patient. This work has extended to the development of educational curricula to promote interprofessional, patient and family-partnered care. Dr. Leykum has also applied complexity science to improving our ability to implement promising interventions across varied clinical systems. Dr. Leykum has received funding from the Department of Veterans Affairs Health Services Research and Development Service, the PCORI, the Josiah Macy Jr. Foundation, and the NIH. She is a Senior Deputy Editor of the *Journal of Hospital Medicine* and a Deputy Editor of the *Journal of General Internal Medicine*.

Shari Ling, MD, is the Deputy Chief Medical Officer for CMS. In this role, she works to help achieve the Agency's overall objective to improve the nation's health and quality of life, and assists Agency leadership in pursuing the following goals: improve the quality and affordability of health care for all Americans, drive American health care towards payment for value, not volume, and lower the rate of growth in America's health care spending. Dr. Ling's committed focus is on the achievement of meaningful health outcomes for beneficiaries and caregivers through the delivery of high quality, person-centered care across all settings. She contributes her clinical expertise as a geriatrician and rheumatologist as a volunteer at the Baltimore VA Medical Center Alzheimer's Disease and Memory Disorders Clinic. Her expertise also contributes to excellence in CMS's work on acute and chronic pain, substance use disorders, antibiotic resistance, nursing home quality, kidney health, palliative care, HIV, opioid-related issues, long-term care, and hospice. Dr. Ling represents CMS on several HHS efforts. She co-leads the clinical services subcommittee for the NAPA federal advisory group and represents CMS on other workgroups to eliminate and prevent health care associated infections and limit the spread of antimicrobial resistant bacteria. Dr. Ling earned a Master's in Gerontology in Direct Service at the Leonard Davis School of Gerontology, an MD degree at Georgetown University School of Medicine, and completed a rheumatology fellowship at Georgetown University Hospital. She completed her Geriatric Medicine fellowship at Johns Hopkins University School of Medicine. She has retained her appointment as part-time faculty in the Division of Geriatrics and Gerontology, Johns Hopkins University School of Medicine. Her current clinical focus and scientific interest is in the care of people with dementia and multiple chronic conditions.

Tabassum Majid, PhD, has had both a personal and professional passion in caregiver-care recipient dyads in AD/ADRD since she was a caregiver for her grandparents. A native Marylander, Dr. Majid received her Bachelor of Science degree from the University of Maryland, Baltimore County (UMBC) concentrating in an interdisciplinary approach to Neurodegenerative Disorders of the Aged. She then gained expertise in dementia from both pre-clinical and clinical perspectives at Baylor College of Medicine while earning a PhD in Translational Biology and Molecular Medicine. She returned to Maryland to complete a fellowship at the University of Maryland School of Pharmacy researching care management decisions with caregivers and individuals with dementia. Dr. Majid has taught, mentored, and supervised many undergraduate and graduate students in her capacity as an Adjunct Faculty member at UMBC and in leading the Integrate Institute, a forward-thinking, nonprofit organization conducting person-centered research, education, and consulting throughout the United States focusing on Alzheimer's disease and related dementias. Projects and collaborations included work with universities, pharmaceutical and technology companies, and other non-profit organizations. Her research philosophy and body of work is currently helping

to provide an evidence base to evaluate both health services and social programs tailored to the needs of both caregivers and their care recipients nationally. Professionally, Dr. Majid is a member of the Alzheimer's & Dementia Disparities Engagement Network convened by USAgainstAlzheimer's and a past appointee on the Maryland Governor's Council on Alzheimer's Disease and Related Disorders, which contributes to the development and implementation of the Maryland State Plan. In 2018, she was named one of The Baltimore Sun's 25 Women to Watch and was also honored as a McKnight's Woman of Distinction 2019 Rising Star. Dr. Majid has several published scientific articles on her work and a book chapter on her personal story.

***Katie Maslow**, MSW, FGSA, is a visiting scholar at the Gerontological Society of America (GSA). The focus of her work is care-related issues for people with cognitive impairment, dementia, and co-existing medical conditions and their family caregivers. She was co-chair of the 2017 National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers and has assisted in gathering stakeholder group input for the 2020 Summit. Before joining GSA in 2016, Maslow was a scholar-in-residence at the Institute of Medicine (IOM), National Academies of Science, in Washington, DC, where she worked on studies of geriatric mental health, cognitive aging, and advanced dementia. She previously conducted policy-related research for the Alzheimer's Association and the U.S. Office of Technology Assessment. She has a social work degree and is GSA fellow.

Elizabeth A. McGlynn, PhD, is Vice President for Kaiser Permanente Research, Executive Director of the Kaiser Permanente Center for Effectiveness and Safety Research (CESR), and Interim Senior Associate Dean for Research and Scholarship at the Kaiser Permanente School of Medicine. She is the senior national executive leader for research for the Kaiser Permanente system and is responsible for implementing the national research strategy. She collaborates with national and regional leadership to assure the contribution of research to improved care for Kaiser Permanente members and the communities in which they live. She is also responsible for oversight of research administration, developing and implementing a strategy for the Kaiser Permanente Research Bank (the enterprise-wide biobank), and two internal research and analytic groups. Dr. McGlynn is an internationally recognized expert on methods for evaluating the appropriateness and quality of health care delivery. Prior to joining Kaiser Permanente, Dr. McGlynn was Associate Director of RAND Health and held the RAND Distinguished Chair in Health Care Quality. She received AcademyHealth's Distinguished Investigator Award in 2012. Dr. McGlynn was elected to the National Academy of Medicine in 2005 and is the Immediate Past Chair of the ABIM Foundation Board of Trustees. She serves on the editorial boards of *JAMA*, *Health Services Research*, and the *Milbank Quarterly* and is the former chair of the National Advisory Council for AHRQ. Dr. McGlynn received her bachelor's degree in international political economy from The Colorado College, her master's degree in public policy from the University of Michigan's Gerald R. Ford School of Public Policy, and her doctorate in public policy analysis from the Pardee RAND Graduate School.

†Nupur Mehta, MD, is the CMO for CareMore Health's East Region overseeing both Medicaid, Medicare, and home-based markets. He is responsible for managing the teams across eight states, monitoring patient outcomes, and helping to grow access to CareMore's suite of comprehensive services. He is a practicing internal medicine physician and is passionate about value-based health care transformation, improving access and quality, and medical education. Prior to CareMore, Dr. Mehta worked at Evolent Health, the Advisory Board Company, and George Washington University Hospital. He is a graduate of Duke and Harvard University and completed his residency training at Brigham and Women's Hospital.

Maggi Miller, PhD, received her BS in biology and chemistry minor from Wesley College in Dover, Delaware and her MS in health promotion from the University of Delaware in Newark, Delaware. She received her PhD in epidemiology from University of South Carolina, Arnold School of Public Health. She completed a postdoctoral fellowship at the Office for the Study of Aging where her research focused on behavioral and psychological symptoms that predict nursing home placement of individuals with Alzheimer's disease. She is currently a Research Assistant Professor in the Department of Epidemiology and Biostatistics at the University of South Carolina and manages the South Carolina Alzheimer's Disease Registry at the Office for the Study of Aging, one of only three population-based state registries of its kind in the US. In addition to her work with the registry, Dr. Miller is a member of the analysis core for the NIA-funded Carolina Center on Alzheimer's Disease and Minority Research providing mentorship to scientists from underrepresented groups to increase diversity of the aging research workforce. She also serves as an external evaluator for a grant that utilizes the REACH program to expand and enhance educational and supportive services to people with AD/ADRD and their caregivers through caregiver coaching and education.

Joan Monin, PhD, is an Associate Professor in the Social and Behavioral Sciences Department at the Yale School of Public Health. She is an internationally recognized leader in the field of aging and an expert on the mental and physical health of caregivers for older adults. Her research goes beyond observational work on caregiving, taking an interpersonal and multimethod approach to understand the emotional lives of caregivers with the goal of developing multifactorial interventions to enhance the quality of life of both caregivers and care recipients. Her basic and translational work on the interpersonal effects of suffering and compassion in caregiving has transformed how caregiving interventions are being developed, with the focus on emotional communication within dyads. She is a pioneer in developing dyadic interventions to help relationships thrive in the early stages of AD/ADRD. Her research, which has been published in the field's highest-impact journals (e.g., *Annals of Behavioral Medicine*, *Health Psychology*), has been referenced in national professional guidelines for caregivers, incorporated into medical school curricula, and featured in national and international media outlets (U.S. News & World Report, BBC News). She has received several awards from the top societies in aging research (e.g., Gerontological Society of America) and continued NIH grant funding throughout her career (e.g. F32, K01, R21, R01). Her reputation has led to leadership roles at two NASEM Expert Meetings (e.g. "Empathy & Compassion"), and she was recognized as one of the top 15 scholars in the world by Harvard's Center for Human Flourishing for her work on suffering and compassion as it applies to health care. Dr. Monin is on the NIA Behavioral and Social Sciences Standing Review Committee and has been commissioned to write papers at NIH.

***Michael Monson**, MPP, is the Senior Vice President of Medicaid and Complex Care at Centene Corporation and the CEO of Social Health Bridge™. Operating in 32 states and with revenue of \$73 billion, Centene Corporation, a Fortune 51 company, is a leading multi-line health care enterprise that provides programs and related services to the rising number of under-insured and uninsured individuals. Michael has national product responsibility for Centene's Medicaid and Complex Care product lines – Temporary Assistance for Needy Families (TANF); Children's Health Insurance Program (CHIP); Foster Care; Medicaid Expansion; Aged Blind & Disabled (ABD); Managed Long-Term Services and Supports (MLTSS); and Medicare-Medicaid Plans (CMS Financial Alignment Demonstration). These products operate across 27 states and collectively comprise ~ 8.5 million members and ~\$43 billion in revenue. Centene is #1 or #2 in national market share for these products. Additionally, Mr. Monson is responsible for Centene's overall strategy for Social Determinants of Health (SDoH), Social Health Bridge Trust™, and the Centene Center for Health Transformation, a collaboration with academic researchers. Previously, Mr. Monson was the Chief Administrative Officer and Vice President of Residential Services at Village Care of New York where he had responsibility for a \$60 million P&L as well as multiple corporate functions. Village Care is a New York City based integrated health system with more than \$200M in revenue.

***Vincent Mor**, PhD, is the Florence Pirce Grant Professor of Community Health in the Brown University School of Public Health and a senior health scientist at the Providence VA Medical Center. He has been principal investigator of more than 40 NIH-funded grants, published more than 400 peer reviewed articles, received the Robert Wood Johnson Foundation health policy investigator award, a MERIT award from the NIA, the Distinguished Investigator Award From AcademyHealth, the John Eisenberg Mentoring Excellence Award from AHRQ, and is a member of NASEM. He was one of the authors of the Congressionally mandated Minimum Data Set (MDS) for Nursing Home Resident Assessment and the architect of an integrated Medicare claims and clinical assessment data base used for policy analysis, pharmaco-epidemiology, population outcome measurement, and cluster randomized clinical trials.

Lisa Onken, PhD, directs the Behavior Change and Intervention program in the Division of Behavioral and Social Research at the NIA. She joined NIA in January 2015 after serving as the Chief of the Behavioral and Integrative Treatment Branch and the Associate Director for Treatment at the National Institute on Drug Abuse (NIDA). Dr. Onken received her PhD in Clinical Psychology from Northwestern University and completed her clinical psychology internship at Cook County Hospital in Chicago. Prior to coming to NIH, she held a variety of academic, clinical, and research scientist positions at Northwestern University, the University of Illinois Medical School, and Walter Reed Army Institute of Research. Dr. Onken administers a broad program of research on the development of behavioral interventions to promote healthy aging, including research on interventions to promote positive affect, reduce negative affect, promote exercise, foster sleep, interventions for those who provide care for individuals with dementia, and other interventions to promote health and well-being. She is a Project Scientist on the NIA-funded IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory and has played an active role in the NIH Science of Behavior Change Common Fund effort since its inception. She leads the Roybal Translational Centers program structured within the framework of the NIH Stage Model, a comprehensive translational conceptual framework for principle-driven behavioral intervention development. She utilizes the NIH Stage Model to develop interventions that are optimally potent and maximally scalable to reach those in need.

Arne Owens is Deputy Assistant Secretary for Planning and Evaluation in the Office of the Assistant Secretary for Planning and Evaluation (ASPE), HHS. Prior to his arrival at ASPE, he served as Deputy Assistant Secretary with the Substance Abuse and Mental Health Services Administration (SAMHSA). Prior to joining the Administration, he served on U.S. Senate staff as health care policy advisor for Sen. Bob Corker (Tennessee) and Sen. David Vitter (Louisiana). Mr. Owens came to Capitol Hill following service in the Commonwealth of Virginia as Chief Deputy Director of the Department of Health Professions. Mr. Owens served previously in HHS during the Bush Administration with SAMHSA and the Administration for Children and Families and, prior to that, in Virginia state government as Deputy Commissioner, Department of Mental Health, Mental Retardation and Substance Abuse Services.

†Ed Patterson was diagnosed with Alzheimer's disease in 2018 at age 71. A Pittsburgh native, Ed moved numerous times to cities across the country as an outsourcing account manager in the banking industry. He retired in 2011 and soon found himself bored by "complete retirement," and began working part-time at Disney World. Ed says it was his husband David who first raised concerns about Ed's cognition. David, a nurse, noticed lapses in Ed's memory and changes in his personality. Ed and David brought their concerns to Ed's primary care physician. His doctor "brushed it off" saying the changes were a side effect of medications Ed was taking and changed his prescription. After several more doctor visits and further cognitive testing, Ed received a PET scan and spinal tap in conjunction with a clinical trial. These tests confirmed Ed's diagnosis of Alzheimer's disease. Ed confesses that he "shut down" as news of his diagnosis set in. It took several weeks before he was able to slowly start sharing his diagnosis with friends and family members. Overwhelmed with the "outpouring of support" he received, Ed decided to use his voice to speak out to raise awareness and educate others on what it's like to live with dementia. Ed works with his local Alzheimer's

Association chapter, sharing his story at education and community presentations. He is also a Team Captain for his local Walk to End Alzheimer's event. As a member of the Alzheimer's Association 2019-2020 National Early-Stage Advisory Group, Ed wants to reduce the stigma surrounding Alzheimer's disease and other dementias. He also wants to stress the importance of funding Alzheimer's research and care and support programs. Ed and his husband David have been domestic partners for 32 years and married for the past four years. They live in Clermont, Florida. Ed has two daughters.

Ronald C. Petersen, PhD, received a PhD in Experimental Psychology from the University of Minnesota and graduated from Mayo Medical School in 1980. He completed an internship in Medicine at Stanford University Medical Center and returned to the Mayo Clinic to complete a residency in Neurology. That was followed by a fellowship in Behavioral Neurology at Harvard University Medical School/Beth Israel Hospital in Boston, Massachusetts. Dr. Petersen joined the staff of the Mayo Clinic in 1986 and became a Professor of Neurology in 1996. In 2000, he was named the Cora Kanow Professor of Alzheimer's Disease Research and Mayo Clinic Distinguished Investigator in 2011. He is currently the Director of the Mayo Alzheimer's Disease Research Center and the Mayo Clinic Study of Aging and has authored more than 960 peer-reviewed articles on memory disorders, aging, and Alzheimer's disease. Dr. Petersen is one of the recipients of the 2004 MetLife Award for Medical Research in Alzheimer's Disease and the 2005 Potamkin Prize for Research in Picks, Alzheimer's, and Related Disorders of the American Academy of Neurology. In 2012, he received the Khachaturian Award and the Henry Wisniewski Lifetime Achievement Award in 2013 from the Alzheimer's Association. In 2011 he was appointed by the Secretary of HHS to serve as the Chair of the NAPA Advisory Council on Alzheimer's Research, Care, and Services, and in 2014, he was appointed to the World Dementia Council by the United Kingdom government.

***Joanne Pike**, DrPH, is chief program officer at the Alzheimer's Association, overseeing the organization's efforts in care, support, and risk reduction for the millions affected by Alzheimer's disease and other dementias. Dr. Pike's work with the Association includes care and support services offered across the organization to those affected by the disease; health system outreach and quality improvement initiatives; long-term care initiatives focused on person-centered care delivery models; and growth strategies for reaching more individuals through quality improvement, education, and supportive programs and services. Dr. Pike is responsible for guiding the implementation of programs to support the Association's dementia care practice recommendations aimed at helping nursing homes, assisted-living facilities and other long-term care and community care providers deliver optimal quality, person-centered care for those living with Alzheimer's and other dementias. In addition, Dr. Pike oversees the implementation of clinical guidelines for care in health systems and public health practice. Prior to joining the Association, Dr. Pike spent 13 years in leadership positions at the American Cancer Society and three years as executive director of the Preventive Health Partnership, a collaboration between the American Cancer Society, the American Diabetes Association and the American Heart Association aimed at preventing cancer, diabetes, heart disease and stroke. Dr. Pike's educational background includes a doctorate in public health leadership, focused on health policy and management, from the University of North Carolina at Chapel Hill.

***David Reuben**, MD, is Director, Multicampus Program in Geriatrics Medicine and Gerontology and Chief, Division of Geriatrics at the University of California, Los Angeles (UCLA) Center for Health Sciences. 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 is a past President of the American Geriatrics Society and former Board Chair, American Board of Internal Medicine. In 2012, Dr. Reuben received one of the first Center for Medicare & Medicaid Innovation (CMMI) Challenge awards to develop a model program to provide comprehensive coordinated care for patients with Alzheimer's Disease and other dementias. In 2014, he was one of three principal investigators to be awarded a multicenter clinical trial (STRIDE) by PCORI and the

NIA to reduce serious falls related injuries; it is the largest grant that PCORI has awarded. Dr. Reuben recently completed a PCORI methodology grant to determine and measure patient and caregiver goals in Alzheimer's disease and dementia. In 2018, he was awarded a multi-site PCORI- and NIA-funded pragmatic trial to compare the effectiveness of health system-based dementia care versus community-based dementia care versus usual care. Dr. Reuben is co-chair of the 2020 National Research Summit in Care, Services, and Supports for Persons with Dementia and their Caregivers and is a member of the NASEM Decadal Survey of Behavioral and Social Science Research on Alzheimer's Disease and Alzheimer's Disease-Related Dementias committee. Dr. Reuben continues to provide primary care for frail older persons, including making house calls. In his spare time, Dr. Reuben has written six plays and lyrics for more than 20 songs with composer Sidney Sharp. A compilation of the first 10 has been recorded.

Laurie Scherrer was diagnosed with early onset Alzheimer's and FTD at the age of 55. Unable to continue a professional career, she turned her focus towards helping others through their dementia journey. Ms. Scherrer serves on the Dementia Action Alliance Board of Directors and Advisory Board. She is a Dementia Mentor, Purple Angel, and active in many support groups. She is frequently a co-host and panel member for Alzheimer's Speaks Radio. She is an international speaker and has been featured in many articles and documentaries including New York Times, AARP, PBC, Dementia 101, South Africa Sunday Times, and the Reading Eagle. Ms. Scherrer is a member of the Persons Living With Dementia Stakeholder Group for the 2020 Summit. On her website www.dementiadaze.com, Ms. Scherrer shares her feelings, challenges, symptoms, and adjustments in hopes of encouraging other persons with dementia and care partners to explore ways to live beyond dementia. Together with her husband Roy, she works hard trying to identify the obstacles that trigger her challenges and symptoms and then figure out what adjustments they can make to overcome the barriers. As Ms. Scherrer says, "We don't automatically accept that I CAN'T do things anymore, instead we try to figure out HOW I CAN."

***Melanie (Lonni) Schicker**, EdD, is a retired professor of Health Administration as well as a Registered Nurse. She holds a Master's in Health Administration and a Doctorate in Education. In 2014 she was diagnosed with mild cognitive impairment and in 2018 was diagnosed with younger onset Alzheimer's and Lewy Body dementia (LBD). She is an avid and outspoken advocate for health care reform and speaks locally and nationally regarding the financial burden of dementia. Dr. Schicker is a 2020 Summit Steering Committee Member, Member of the Board of Directors for the Alzheimer's Association of Greater Missouri, and a National Speaker for Living Well with Alzheimer's and the Financial Burden of Dementia. She works tirelessly to reduce the stigma associated Alzheimer's and related dementias.

†**David Sims** was born and raised in Arkansas, the youngest of the siblings. Growing up in a musical home, David started piano lessons at the age of 8 and sang in the church and school choirs. After high school David attended Ouachita Baptist University on a full music scholarship with a major in voice. After college and being disillusioned with the salaries of music teachers and the prospect of working multiple jobs, David enrolled in nursing school and graduated in 1982. In 1984 while living and working in Little Rock, Arkansas, David met Ed Patterson. After a 3-year friendship they started their life together in 1987. Ed's work in the banking software industry gave them the opportunity to live in California, Indiana, Maine, and now Florida. On January 6, 2015, the day that the ban on marriage equality was lifted in Florida, David and Ed were married by Orlando's Mayor Buddy Dyer. David considers his life and marriage with Ed by far his greatest accomplishment. In 2016 David started noticing changes in Ed's cognition, difficulty with remembering appointments and making airline reservations, and quick mood changes. Initial neurology workups were inconclusive, but David remained steadfast that something was not right. In 2018, Ed finally received a diagnosis of mild cognitive impairment (MCI). Amyloid PET imaging revealed a high plaque burden. The diagnosis was a serious blow, but David and Ed found support through the Alzheimer's Association. Both wanting to make a difference and break down

the stigma surrounding Alzheimer's, they now use their voices to advocate to state and national legislators for more research and funding, and to speak and educate in the community to raise awareness as one of the many faces of Alzheimer's disease and not its victim. David currently lives in Clermont Florida with Ed. He works as a nurse at Orange County Corrections and Lake Correctional Institute.

Joanne Spetz, PhD, is a Professor at the Institute for Health Policy Studies at the University of California, San Francisco, and Associate Director for Research at Healthforce Center at UCSF. She is the principal investigator and director of the UCSF Health Workforce Research Center on Long-Term Care, which engages researchers at UCSF and other organizations to lead research to guide policy and practice that will ensure the health care needs of the rapidly-aging U.S. population are met in the future. Dr. Spetz has conducted research on health workforce labor markets, education, shortages, and employment for more than 25 years. She has been the principal investigator of national and state surveys of registered nurses and nursing schools, including the 2008 National Sample Survey of Registered Nurses and the ongoing California Board of Registered Nursing Surveys of Registered Nurses and Schools Surveys. She also has led research on the impact of the Affordable Care Act on the health workforce, the impact of regulations in the hospital industry, effects of health information technology on hospital staff and patients, and quality of patient care. Dr. Spetz is a member of the Committee on Consideration of Generational Issues in Workforce Management and Employment Practices for NASEM and previously served on the Institute of Medicine Standing Committee on Credentialing Research in Nursing. She is an Honorary Fellow of the American Academy of Nursing.

David Stevenson, PhD, is currently a Professor of Health Policy in the Department of Health Policy at Vanderbilt University School of Medicine. Dr. Stevenson's primary research interests are long-term care and end-of-life care. His previous work has focused on a broad range of topics in these areas, including the evolution of Medicare's hospice benefit, end-of-life care for nursing home residents, long-term-care financing options for the future, and the role of ownership in the provision of nursing home and hospice care. Dr. Stevenson maintains a strong focus on educational activities. He is Vice-Chair for Education in his department, serves as Health Policy track director in Vanderbilt's Master of Public Health program, and recently became the inaugural holder of an endowed Directorship in Health Policy Education. He has worked in various research and policy settings, including the U.S. Public Health Service, the University of Washington School of Public Health, and the Urban Institute. Dr. Stevenson received a BA in religion from Oberlin College, a SM in health policy and management from the Harvard School of Public Health, and a PhD in Health Policy from Harvard University. His previous faculty appointment was in the Department of Health Care Policy at Harvard Medical School from 2004-2013.

***Robyn Stone**, DrPH, Senior Vice President for Research at LeadingAge and Co-director of the LeadingAge LTSS Center @UMass Boston, has more than 40 years of experience as a researcher and policy maker in long-term care and aging services. Dr. Stone has developed and managed many studies to identify best practices in aging services delivery, evaluate program processes and implementation and assess outcomes for consumers, staff, and organizations. She has spearheaded the LTSS Center's major applied research initiatives in several areas, which include identifying and testing models that link affordable senior housing with health-related and supportive services to allow residents to age in place and developing a quality aging services workforce. Dr. Stone also serves as a bridge between the research and policy and practice communities at the federal, state, and local levels. She served on the National Advisory Council for the Bipartisan Policy Center's Taskforce on Senior Housing and Health. As a National Academy of Medicine member, she serves on several committees including the Health Sciences Policy Board and the Committee on Care Interventions for Individuals with Dementia and their Caregivers. Dr. Stone is a member of the Center for Health and Social Care Integration National Advisory Board and the NIA-funded IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory Stakeholder Engagement Team. She is currently consulting with government officials in Singapore on a regional housing plus services initiative.

†**Clare Stroud**, PhD, is a Senior Program Officer with NASEM in Washington, DC. In this capacity, she serves as Director of the Forum on Neuroscience and Nervous System Disorders, which brings together leaders from government, industry, academia, and patient advocacy organizations to discuss key challenges and emerging issues in neuroscience research, development of therapies for nervous system disorders, and related societal issues. She recently served as Director for a major study titled Preventing Cognitive Decline and Dementia: A Way Forward, which was released in July 2017. She previously directed projects in areas such as clinical research data sharing, young adult health and well-being, and disaster preparedness in health systems. Dr. Stroud first joined the National Academies as a science and technology policy graduate fellow. She has also been an Associate at AmericaSpeaks, a non-profit organization that engaged citizens in decision making on important public policy issues. Dr. Stroud received her PhD from the University of Maryland, College Park with research focused on the cognitive neuroscience of language and face perception. She received her bachelor's degree from Queen's University in Canada and spent a year at the University of Salamanca in Spain.

Craig W. Thomas, PhD, is the Director of the Division of Population Health within CDC's National Center for Chronic Disease Prevention and Health Promotion where he directs a broad portfolio of programmatic and applied research activities focused on improving population health across the lifespan. Specific topic areas include Alzheimer's disease, aging, arthritis, epilepsy, wellbeing, school health, tribal health, and population health data and analytics based on the Behavioral Risk Factor Survey System and 500 cities. Dr. Thomas joined CDC in 1998 where he has held leadership positions within a variety of public health programs including CDC's HIV and AIDS Prevention Program, The Guide to Community Preventive Services, the Public Health Preparedness and Response Program, the National Public Health Improvement Initiative, and the PHHS Block Grant. Most recently Dr. Thomas served as Director of the Division of Public Health Performance Improvement within the Center for State Tribal, Local, and Territorial Support (CSTLTS). Dr. Thomas earned a PhD in social psychology and applied research methods from Claremont Graduate University, a MS in experimental psychology from California State University Fullerton, and a BA in biological sciences from the University of California Irvine. He has authored more than 30 peer-reviewed publications, coauthored three book chapters, and taught several courses in public health practice, evaluation, and applied research methods.

Thomas Trivison, PhD, is a biostatistician who works in observational and interventional science promoting physical and cognitive function in aging. He is Associate Professor at Harvard Medical School; leads the Biostatistical Design and Analysis Core of the NIA-funded Boston Pepper Older Americans Independence Center; and is Associate Leader of the Design and Statistics Core of the NIA-funded IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory. Dr. Trivison received a bachelor's degree in mathematics from Skidmore College and a PhD in biostatistics from the Johns Hopkins University School of Public Health. His observational research has made important contributions to the epidemiology of aging at the interface of physical function, endocrinology, and cognition, and he has designed and analyzed numerous clinical trials of multimodal interventions in older populations. His quantitative science laboratory develops tools and methods for data visualization and for enhancing the reproducibility of biomedical research in aging.

Laura Trejo is responsible for the administration of the Los Angeles Department of Aging serving one of the largest and most diverse concentrations of older persons in the U.S. She serves as technical and policy advisor to the Mayor and City Council. Since 2016, she has served as lead for Purposeful Aging L.A. an age-friendly initiative “to make the Los Angeles region the most age friendly in the world.” Ms. Trejo is lifelong Trojan with a Master of Science in Gerontology, a Master of Public Administration and currently pursuing a doctorate in social work. She consults and trains nationally and works with individual countries and international organizations to develop initiatives and programs in the areas of aging. Her work has been published in professional journals, book chapters, and major reports. Ms. Trejo’s commitment to excellence have earned many awards and recognition for excellence and innovation, and the United States Library of Congress has recognized Ms. Trejo’s accomplishments as a force for social change.

Jürgen Unützer, MD, MPH, MA, is an internationally recognized psychiatrist and health services researcher. His work focuses on innovative models of care integrating mental health and general medical services and translating research on evidence-based mental health care into effective clinical and public health practice. He has more than 300 scholarly publications and is the recipient of numerous federal and foundation grants and awards for his research. He is Professor and Chair in the Department of Psychiatry and Behavioral Sciences at the University of Washington (UW). He directs the Garvey Institute for Brain Health Solutions at UW Medicine and holds adjunct appointments as Professor in the School of Public Health (in the departments of Health Services and Global Health). Dr. Unützer founded the AIMS Center (<http://aims.uw.edu>) which is dedicated to ‘Advancing Integrated Mental Health Solutions.’ He led the development and testing of IMPACT, an evidence-based model of depression care that has been implemented in more than 1,000 primary care clinics in the U.S. and abroad. IMPACT has been shown in randomized controlled trials to double the effectiveness of usual care for depression while lowering long-term health care costs. Dr. Unützer has served as Senior Scientific Advisor to the World Health Organization and as an advisor to the President’s New Freedom Commission on Mental Health. He works with national and international organizations to improve behavioral health care for diverse populations. His awards include the Beeson Physician Faculty Scholars Award from the American Foundation for Aging Research, the Klerman Junior and Senior Investigator Awards from the Depression and Bipolar Support Alliance, the Distinguished Scientist Award from the American Association of Geriatric Psychiatry, the Research Award from the Academy of Psychosomatic Medicine, the Senior Health Services Scholar Award from the American Psychiatric Association, and a Lifetime Achievement Award from the Association of Medicine and Psychiatry.

Kimberly Van Haitsma, PhD is an Associate Professor of Nursing at the Pennsylvania State University College of Nursing. Dr. Van Haitsma is a geropsychologist whose research focuses on assessment, clinical interventions, and implementation strategies to enhance wellbeing among older adults, particularly those living with dementia. Currently, she is involved in projects to assess a person-centered implementation approach to reduce behavioral and psychological symptoms of distress for those living with dementia in nursing homes; a statewide project to improve the quality of dementia care in Ohio; and is an advisory member on the NIA-funded IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory Dissemination and Implementation Core. Her work has been supported by the NIH, Ohio Department of Medicaid, Alzheimer’s Association, The John A. Hartford Foundation and The Commonwealth Fund. Dr. Van Haitsma has published 90 articles in scientific journals. She is a fellow of The Gerontological Society of America and director of the Program for Person-Centered Living Systems of Care at Penn State University.

David Wendler, PhD, is a senior investigator and Head of the Section on Research Ethics in the Department of Bioethics at the NIH Clinical Center. He is a philosopher trained in the philosophy of science and metaphysics and epistemology. Dr. Wendler is an attending on the Bioethics Consultation service and has served as a consultant to numerous organizations, including the Institute of Medicine, the World Health Organization, and the World Medical Association. His current research focuses on clinical trials and clinical care with individuals who are unable to give informed consent.

Rachel Whitmer, PhD, is Professor of Public Health Sciences and Chief of the Division of Epidemiology at the UC Davis. Professor Rachel Whitmer leads the Population Science of Brain Health Laboratory at UC Davis and is Associate Director of the UC Davis Alzheimer's Disease Center. Her research focuses on using epidemiological methods to reduce inequities in brain aging, especially through study of dementia incidence, cognitive aging, and brain pathology in racial and ethnic minority groups, those with type 1 and type 2 diabetes, and individuals living beyond age 90. Dr. Whitmer is principal investigator of several NIH-funded large cohort studies of dementia and cognitive aging following more than 4,000 people, as well the US POINTER Northern California site. Dr. Whitmer also has a leadership role in the IDEAS study leading analyses for health outcomes. Professor Whitmer was the first female 'Target of Excellence' hire to the School of Medicine at UC Davis, a special hiring mechanism to attract high-impact faculty. Prior to UC Davis she was a Senior Scientist at Kaiser Permanente Division of Research and faculty at University of California San Francisco Department of Epidemiology Biostatistics; she currently holds adjunct appointments at both institutions. Dr. Whitmer's research programs leverage population science and epidemiology to inform cognitive and brain aging in diverse populations that have historically been excluded from research. Dr. Whitmer was the Chair of the Scientific Program for the AAIC from 2016-2018 and is currently an ELAM (Executive Leadership in Academic Medicine) Fellow at Drexel School of Medicine, class of 2019-2020.

†**Arnetta Whittaker** was born and raised in Washington, D.C., the city she still calls home. A graduate of Roosevelt Senior High School, Ms. Whittaker became a certified home care aide in 1985 by completing a training program at Home Care Partners and passing a national certification exam. Soon after completing her training, Ms. Whittaker was hired by Home Care Partners where she has worked for more than 30 years. In 2005, Ms. Whittaker was selected by her peers as Home Care Aide of the Year and was promoted to Stand-By aide in 2013. Ms. Whittaker is ordained as a pastor providing counseling, information and assistance for the women of her church.

***Jennifer Wolff**, PhD, is the Eugene and Mildred Lipitz Professor in the Department of Health Policy and Management and Director of the Roger C. Lipitz Center for Integrated Health Care at the Johns Hopkins Bloomberg School of Public Health and holds a joint appointment in the Division of Geriatric Medicine and Gerontology at the Johns Hopkins University School of Medicine. Dr. Wolff's research focuses on understanding the experiences of older adults and their family caregivers in care delivery and developing applied strategies and initiatives to better support them. She serves as a member of the NASEM Consensus Committee "Care Interventions for Individuals with Dementia and Their Caregivers" and participated in the NASEM Consensus Committee that drafted the report "Families Caring for an Aging America." Dr. Wolff is currently leading initiatives to improve communication in primary care for persons with serious illness through more effective and purposeful engagement of family caregivers. She is a member of the Steering Committee of the National Health and Aging Trends Study (NHATS), and together with Dr. Vicki Freedman from University of Michigan, co-leads the National Study of Caregiving (NSOC). Dr. Wolff is co-chair of the 2020 National Research Summit in Care, Services, and Supports for Persons with Dementia and their Caregivers.

***Sheryl Zimmerman**, PhD, is a University Distinguished Professor of Social Work and Public Health, and for more than 20 years has been Co-Director of the Program on Aging, Disability, and Long-Term Care, Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill. She is internationally recognized as a leader in research related to care and outcomes for people living with dementia, and in 1996, founded the Collaborative Studies of Long-Term Care, the largest ongoing research consortium of almost 1,500 nursing home and assisted living settings that have participated in more than 70 projects with continuous funding from the NIA, AHRQ, and foundations. Key among her efforts are pragmatic and clinical trials, and quality improvement projects, to improve dementia care and outcomes, including to reduce falls, decrease agitation, lessen pain, optimize antibiotic prescribing, improve dementia care practices, and facilitate family-staff interactions. Dr. Zimmerman has received two career awards from the NIA, written five books and more than 350 manuscripts, and is Co-Editor-in-Chief of the *Journal of Post-Acute and Long-Term Care Medicine*. She works closely with long-term care providers and provider organizations, including with the Alzheimer's Association to develop their 2018 Dementia Care Practice Recommendations. Recently, Dr. Zimmerman was recognized as the nation's top-ranked social work scholar in aging. She served as chair of the Social Research, Policy, and Practice Section of the Gerontological Society of America (GSA) and is currently on the GSA Board of Directors. Also, she is on the executive committee of the Patient and Caregiver Reported Outcomes Core of the NIA-funded IMbedded Pragmatic AD/ADRD Clinical Trials (IMPACT) Collaboratory and is co-lead of the Alzheimer's Association's Interdisciplinary Consortium to Improve Care and Outcomes for Persons Living with Alzheimer's and Dementia.

Julie M. Zissimopoulos is Associate Professor in the Sol Price School of Public Policy at the University of Southern California. In addition to her faculty appointment, she serves as Director of Aging and Cognition Research Program and Research Training at the Schaeffer Center for Health Policy and Economics. She is co-director of USC's NIA-funded RCMAR, which is focused on reducing burden of Alzheimer's disease. Her research applies insights and methods from economics to several health policy areas such as risk and health care costs of Alzheimer's disease, medical expenditures, caregiving and financial support between generations of family members. Dr. Zissimopoulos is currently leading several NIA-funded research projects on the health of caregivers for persons with dementia; the use of and response to drug therapies for non-Alzheimer's disease and related dementia conditions that influence risk of dementia; racial and ethnic disparities in diagnosis and health care treatment for dementia; and measuring incidence and prevalence of dementia using Medicare claims and survey data. Her recently published research appears in numerous publications such as the *Journal of the American Medical Association Neurology*, *Journal of Gerontology Social Science*, *Journal of the American Academy of Arts and Sciences*, *Journal of Health Economics*, and *Alzheimer's & Dementia*. Her research on the economics of aging is disseminated through media outlets such as the New York Times, Washington Post, Los Angeles Times, CNN, National Public Radio. Dr. Zissimopoulos received her BA summa cum laude from Boston College, her MA from Columbia University, and a PhD in economics from UCLA.

The background of the page is a solid blue color with a complex, low-poly geometric pattern. The pattern consists of numerous overlapping triangles and polygons of various sizes and orientations, creating a textured, crystalline appearance. The colors range from a deep, dark blue to a lighter, medium blue, with the darker shades forming the outlines and the lighter shades filling the interior of the shapes.

POSTER PRESENTATION ABSTRACTS

Poster Presentation Abstracts

*These poster presenters were selected to provide brief oral remarks at the originally planned Summit in March 2020 during a Lightning Round.

SCIENTIFIC POSTERS

A Dementia-Friendly Faith Village Community Program to Support African American Families

Author: **Fayron Epps**

We recognize that faith communities are important outlets for providing health related information and offering connection to services, particularly for African Americans. This poster will describe the characteristics and implementation of a community program grounded in predominantly African American churches to support families affected by dementia, "Dementia-Friendly Faith Village Community Program". This program offers educational sessions that: (a) provide critical information; (b) emphasize the importance of early detection; and (c) introduces clinical research opportunities. African American churches that are partnering with the program agree to mandatory and customized activities to implement in their church to create a dementia-friendly faith village. The program has partnered with several churches representing six Christian-based denominations in the metropolitan Atlanta area. Ultimately, this program allows for faith leaders and communities to begin the process of becoming dementia-friendly, thus enabling congregations, communities, and persons living with dementia to continue living in meaningful ways.

A Participant and Relationship-Oriented Approach to Dementia Research Recruitment and Engagement: The Brain Health Community Registry

Author: **Andrea Gilmore-Bykovskyi**

Existing paradigms and practices around dementia research recruitment often do not recognize or respond to priorities, concerns, and constraints relevant to participants from diverse backgrounds. To address these gaps, we aimed to develop and apply a research recruitment and engagement model that centers and prioritizes research participant needs, and systematically address socioeconomic determinants (i.e., unmet needs) that may limit accessibility of research. These approaches were pilot tested through a brain health research registry for adult participants and dementia caregivers. The resultant Participant and Relationship-Oriented Research Engagement Model highlights participants' values and perspectives of research as a relationship, emphasizing the importance of equity, reciprocity and transparency. In applying these principals, the Brain Health Community Registry was designed to incorporate proactive, systematic evaluation of potential unmet needs, and connections to relevant services. The resulting model offers a more nuanced understanding of factors that impact research participation including fundamental determinants, among other factors.

Access to Physician Care in Skilled Nursing Facilities (SNFs): Disparity by Degree of Cognitive Impairment

Author: **Kira Ryskina**

Persons with dementia admitted to SNFs have complex medical needs, however, little is known about their access to timely physician care. In this retrospective study of 2,392,753 hospital discharges to SNFs in 2012-2014, we used Medicare claims and nursing home Minimum Data Set (MDS) to measure the time from a patient's admission to a visit by a physician or advanced practitioner and to calculate the MDS 3.0 Cognitive Function Scale. Probability of any visit and the time to visit in days were estimated for patients with and without cognitive impairment using regression models that adjusted for patient and facility characteristics and included SNF fixed effects to account for differences in practice between facilities. Patients with more severe cognitive impairment were more likely to experience delayed or missing physician or advanced practitioner visits. Understanding and correcting this disparity in access to physician-level care in SNFs may improve patient outcomes in SNFs.

Aging in Place for Persons with Dementia: Disparities in Access to Home- and Community-Based Services and Effects on Health

Author: **Regina Shih**

We examine whether greater access to home- and community-based services (HCBS) leads to better health and functioning among persons with Alzheimer's disease and related dementias. We analyzed data from three sources: Medicare Current Beneficiary Survey, Medicare fee-for-service claims, and the Provider of Services File for county-level information on home health providers. For the overall population, we find a significant association between access to a greater number of home health providers in the county per 1,000 adults ages 50 and older and better self-rated health. For persons with dementia, greater home health provider access in their county is even more strongly related to better self-rated health. This suggests that access to HCBS providers is even more important for the health of people with dementia compared to those without dementia. We also qualitatively describe barriers that dementia stakeholders, Medicaid administrators, and providers identified in accessing HCBS by rural/urban residence, race/ethnicity, and stages of dementia.

Black-White Differences in Characteristics and Experiences of Dementia Caregivers

Author: **Chanee Fabius**

Black Americans have a substantially higher prevalence of dementia, are diagnosed at a later stage of disease, and have higher mortality rates compared to other racial and ethnic groups. These persistent racial differences likely affect the experiences of family and unpaid caregivers, although available evidence primarily draws from small convenience samples. Guided by Pearlin's Stress Process Model, we examine race differences in caregiving characteristics, context, stressors, available resources, and experiences among dementia caregivers, drawing from the 2015 National Health and Aging Trends Study (NHATS) and its linked National Study of Caregiving (NSOC). Findings demonstrate that despite providing higher intensity care with constrained financial resources, black caregivers more often report positive experiences. Results emphasize the need to disseminate interventions to support community-dwelling older adults and their family and unpaid caregivers within the context of population aging, projected increases in dementia prevalence, and the growing heterogeneity of older adults and American families.

Changes in Physical and Mental Health of Black, Hispanic, and White Caregivers and Non-Caregivers Associated with Onset of Spousal Dementia

Author: **Johanna Thunell**

An estimated 15 million Americans provide 17 billion hours of unpaid care for persons with dementia. Although caregiver health has been a key research area, few studies examined dementia caregivers and racial/ethnic disparities. A difficulty in estimating this relationship is that poor health could be due to health status before becoming caregivers and/or the impact of caregiving. We use longitudinal data on older couples from the NIA-funded Health and Retirement Study to analyze the relationship between dementia onset and caregiving on caregiver health among a diverse, representative sample. We estimate models that account for unobserved individual differences fixed over time, including (un)healthy selection into caregiving. We found evidence of selection into caregiving, which differed across race/ethnicity. Black and Hispanic, but not white persons, who became caregivers had poorer health before becoming caregivers than those who did not become caregivers, but there were no differential changes in health after becoming caregivers.

*Cognitive Training to Promote Healthy Aging in Caregivers of a Loved One with Dementia: Rationale and Methods for Targeting Mechanisms to Improve Caregiver Interventions

Authors: Kathi Heffner, **Maria M. Quiñones**, Autumn Gallegos, Silvia Sorensen, Carol Podgorski, Mia Weber, & Hugh Crean

Chronic stress exposure inherent to caregiving for a loved one with AD/ADRD accelerates aging-related declines in cognitive and immune function. Behavioral interventions are sorely needed to promote caregivers' ability to adapt to caregiving stressors, thereby minimizing caregiving's health risks. For older caregivers, aging- and chronic stress-related changes in shared neural pathways may lead to poor cognition, emotion and stress regulation, and in turn, increase susceptibility to poor health. Our overall objective is to target and strengthen these shared neural pathways to support caregivers' overall adaptive capacity. In our current randomized controlled trial (RCT) (R01AG049764), we are testing whether visual speed of processing and attention training will strengthen caregivers' capacity for stress adaptation, and, ultimately, slow aging-related declines in immune function. With this RCT, we aim to understand cognitive training as a potential intervention for caregiver stress, and more broadly, to support healthy aging in caregivers.

*Competency Based Training for In-Home Supportive Services Providers of Consumers with ADRD

Author: **Lourdes Guerrero**

IHSS providers play a crucial role in maintaining the health and well-being of community-dwelling older adults. Yet, most IHSS caregivers receive little to no training in caring and monitoring the health and well-being for their consumers, especially for those with AD/ADRD. The UCLA Geriatrics Workforce Enhancement Program entered into a partnership with the California Long-Term Care Education Center to develop, implement and evaluate a comprehensive training curriculum for IHSS caregivers. The 10-week, 35-hour program consisted of training modules with topics ranging from roles and rights of the care recipient to assisting with personal hygiene, with a focus on managing AD/ADRD-related behaviors. There were statistically significant gains post intervention in overall confidence in caregiving skills and knowledge among all participants. Our results point to gains in caregiving skills that can be achieved through training, and the importance of collaborating with community-based organizations to deliver such training.

Contribution of Alzheimer's Disease and Related Dementias to U.S. Mortality: Findings from the Health and Retirement Study

Author: **Andrew Stokes**

Vital statistics are the primary source of data on the impact of dementia on U.S. mortality levels, despite evidence that dementia is underreported on the death certificate. Alternative estimates of the contribution of dementia to U.S. mortality levels, drawing on high-quality population-based samples, are urgently needed for health policy and planning. We estimate the percentage of deaths attributable to dementia in the U.S. and quantify the extent to which the burden is underestimated using death certificate data. Our findings indicate that the percentage of deaths attributable to dementia was 9.0 percent [95 percent CI, 7.7-10.3], translating to an excess of 143,000 [CI 123,000-163,000] deaths annually. The percentage of deaths in which dementia was assigned as the underlying cause of death (4.4 [CI, 3.7-5.2]) underestimated the contribution of dementia by approximately a half. Incorporating deaths attributable to cognitive impairment, not dementia (CIND) into the comparison resulted in even greater underestimation of the dementia burden.

*Dementia is Associated with Increased Mortality and Poor Patient-Centered Outcomes After Vascular Surgery

Authors: Samir Shah, Ginger Jin, Amanda Reich, Avni Gupta, Michael Belkin, and **Joel Weissman**

We sought to evaluate the association of dementia with outcomes after vascular surgery. We reviewed claims data for Medicare Part A fee-for-service insurance beneficiaries in 2011 who underwent inpatient vascular surgery. Our study included 210,918 patients, of which 27,920 carried a diagnosis of dementia. The overall average age was 75.74 years, and 55.43 percent were male. Patients with dementia were older and had higher rates of comorbidities. Emergent/urgent cases were more frequent amongst patients with dementia (60.66 percent vs 37.93 percent, $p < 0.001$). After adjustment, patients with dementia had increased odds of 90-day mortality (OR 1.63, $p < 0.0001$), extended SNF stay (OR 3.47, $p < 0.0001$), and longer hospital stays (8.29 vs. 5.41 days, $p < 0.001$). They were less likely to be discharged home (OR 0.31, $p < 0.0001$) and spent a lower fraction of time at home after discharge (63.29 percent vs 86.91 percent, $p < 0.001$). These data should be used to counsel patients with dementia facing vascular surgery to provide goal-concordant care.

Developments in the Market for Assisted Living: Residential Care Availability in 2017

Author: **Wenhan Zhang**

Assisted living (AL) residences have become an important provider for dementia population. The aim of this study is to describe how the variation in supply of AL is associated with county-level characteristics. We compiled lists of AL facilities licensed in 2017 and obtained county-level data from Area Health Resource File. We divided counties into five categories: no AL and quartiles from 1 (low penetration) to 4 (high penetration). Among states where data is available, we divided counties into three categories: no AL, AL present without dementia-specialized unit, and at least one dementia-specialized AL present. We found AL communities are disproportionately located in markets with higher education attainment and wealth, fewer minorities, and lower rates of unemployment and poverty. Following similar trends, dementia-specialized communities are disproportionately located in affluent, urban markets with higher education levels. It warrants future work to understand how AL policies will affect access and care for vulnerable population.

Does Spouse's Dementia Diagnosis Make Individuals Skimp on Health Care?

Author: **Yi Chen**

Substantial time and financial resources taken away by living with persons with dementia may make their spouses forgo needed health care, elevating downstream health care costs. To quantify the effect of dementia on spouses' health investment, I employed a difference-in-difference approach, comparing use of preventive services and doctor visits before and after spouses' dementia onset. Primary analysis of Health and Retirement Study data with linkage to Medicare claims reveals that individuals whose spouse had dementia did not change their use of most health services, relative to dementia-free controls; however, middle-class individuals skimped on flu shot and diabetes screening. Providing help for activities of daily living (ADLs) to persons with dementia was associated with fewer doctor visits, especially among females. Thus, externalities of dementia imposed on family members are more profound and complex than deprivation of time. Certain subgroups were worse off when facing the trade-off between caring for demented spouses and caring for themselves.

Estimating Provider, Ambulatory Care, and Emergency Department Use by ADRD and Non-ADRD Patients in the Southern Community Cohort Study

Authors: **Laura Keohane and Sayeh Nikpay**

As of 2019 there are an estimated 5.6 million Americans aged 65 or greater with Alzheimer's disease, which is projected to grow to 13.8 million by mid-century. Studies have shown that one way to reduce costs and improve health is by increasing ambulatory care usage in the AD/ADRD population. We provide further evidence on this topic by estimating ambulatory care use, site of ambulatory care, and its correlation with health care use and cost, especially in the emergency department (ED). We use data from the Southern Community Cohort Study (SCCS), an ongoing prospective cohort study of low-income adults in 12 Southeastern states. Our findings suggest that AD/ADRD patients are more likely to use the ED and have both higher utilization and health care costs than non-AD/ADRD patients. Our findings suggest that evaluating the treatment channels for these patients is key to reducing costs faced.

Family Quality of Life Among Sexual and Gender Minority Caregivers of People with Alzheimer's Disease and Related Dementias

Author: **Joel Anderson**

Little is known about the unique experiences of sexual and gender minority (SGM) caregivers of people with AD/ADRD and the consequences of these overlapping identities. An ongoing study is using digital methods to assess psychosocial measures within this caregiving population. As of November 2019, the majority of respondents are gay men (62 percent). Most are white (80 percent) with a third identifying as Latinx. Approximately one-third (34.5 percent) are college graduates, live in a large city (37.2 percent) or a small town (33.6 percent), report a moderate to high level of stress (39.3 percent), and find it somewhat difficult to afford the basics (31 percent). The majority are providing care for someone who identifies as lesbian, gay, or bisexual (70 percent), with 20 percent caring for someone transgender. Moreover, 82 percent report experiencing depression-related symptoms. This ongoing study is the first to provide data vital to understand the unique needs of SGM caregivers of people with ADRD.

Hearing and Dementia: Applying User-Driven, Community-Delivered Hearing Care to Address Disparities

Author: **Carrie Nieman**

Age-related hearing loss is highly prevalent among persons with dementia (PWDs) and individuals with sensory loss are at an increased risk for neuropsychiatric symptoms. However, few older adults use hearing aids and disparities in hearing care exist among vulnerable populations given barriers to traditional clinic-based care and may be especially challenging for PWDs and their care partners. PWDs and, in particular, minority older adults with cognitive impairment, have some of the lowest rates of hearing aid use. To address this gap, this poster will share the latest from two ongoing NIA-funded studies focused on the development and piloting of affordable, accessible communication interventions designed for PWDs and their care partners delivered in the home and integrate low-cost, over-the-counter hearing technology. With an embedded social design fellow, these studies build our understanding of participatory, co-design with PWDs and their care partners through a mixed methods approach.

*How Dementia Family Caregivers Proxy Assess Quality of Life

Author: **Patricia Egan**

Dementia care prioritizes quality of life (QOL) as a care outcome. As dementia progresses, family caregivers are routinely enlisted as proxy assessors of QOL. This is not ideal because proxy- and self-assessments differ systematically (Orgeta, et al., 2015) and because reporting about another's difficulties may be distressing (Lamm, et al., 2007). Better understanding of how family caregivers' proxy assess QOL could enhance understanding of dementia-related QOL assessments. This mixed method study explored the cognitive and affective processes of 36 dementia family caregivers while proxy-assessing QOL from different perspectives using the Quality of Life-Alzheimer's Disease (QOL-AD) (Logsdon, et al., 1999). Cognitive processes included perspective switch, projection, and comparison. More positive affect was associated with assessing from the care recipient's perspective than from proxy's own perspective. Most QOL domain scores changed when proxies changed perspectives. Specification of perspective in proxy reports matters for QOL measurement and caregiver feeling.

Implications of 2020 Skilled Home Health Care Payment Reform for Persons with Dementia

Author: **Claire Ankuda**

Medicare home health provides episodic home-based clinical care to the growing population of community-dwelling persons with dementia. Home health payment recently changed: episodes shortened from 60 to 30 days and episodes initiated in the community are now reimbursed at relatively lower rates. We used the Medicare claims-linked National Health and Aging Trends Study to assess home health use patterns in 1,867 older adults using home health from 2011-2017. Over an average follow-up of 4 years, 50.2 percent of persons with dementia used home health as compared to 15.3 percent of persons without dementia. Most home health provided to persons with dementia was initiated in the community (61 percent), compared to 37 percent for persons without dementia. Persons with dementia were more likely to receive care in days 31-60 of the episode compared to those without dementia. Home health payment changes may disproportionately impact the highly vulnerable population of older adults with dementia.

Innovating Dementia and Caregiving Research Recruitment through Care Community Partnerships

Authors: **Michael Splaine and Erin Beck**

Despite the prevalence of research opportunities, including drug therapies, assistive technologies and social care interventions, difficulty recruiting participants remains a barrier to completion of dementia and caregiving research. Adult Day Services (ADS) have a unique and valuable opportunity to navigate persons with dementia and their caregivers through a process of increased research awareness, interest, and participation. ADS provide the most affordable care and serve the most racially and ethnically diverse participants among the long-term care service sector. There are an estimated 5,000 centers across the U.S. providing care to nearly 300,000 participants, of which the majority are older adults and approximately half have dementia. Results on three studies recruiting through ADS will be discussed, as well as best practices and next steps for developing partnered recruitment activities with ADS.

***Medical Costs Attributable to Caregiving for a Spouse Diagnosed with Alzheimer's Disease and Related Dementia (ADRD): Preliminary Results**

Author: **Bailey Ingraham**

Informal caregiving is a critical component of support for persons with AD/ADRD, but there are few estimates quantifying how informal caregiving directly impacts caregivers' health care utilization and costs. This poster will present data from the NIA-funded Health and Retirement Survey (HRS) linked with claims data to determine the 5-year incremental medical cost to caregivers of persons newly diagnosed with AD/ADRD compared to caregiving spouses of persons without AD/ADRD. Spousal caregivers will be matched to control spousal caregivers based on their own characteristics (HRS entry year, age, sex) and those of their partner (sex, age). Total unadjusted Medicare and Medicaid costs by year (1-year pre- and 5 years post-onset) will be summarized for the matched population, along with rates of transition to long term care and mortality. Sub-analyses will stratify results by gender and race and ethnicity of the spousal caregiver.

***MOVING TOGETHER: Livestream Virtual Group Movement Classes for Persons with Dementia and Caregivers: Feasibility and Satisfaction**

Author: **Deborah Barnes**

Paired PLIÉ (Preventing Loss of Independence through Exercise) is an in-person, group movement program for persons living with dementia (PLWD) and caregivers (CGs) that includes physical movements, mindful body awareness, and social engagement. In partnership with Together Senior Health, we tested feasibility and satisfaction with a livestream, virtual group format. Study participants were 11 PLWD (36 percent women, 78±12 years) and 10 CGs (70 percent women, 70±16 years). Fifteen (8 PLWD, 7 CGs) completed the 12-week program, and all reported high satisfaction. Participants described physical, social and emotional benefits of participating online. The main challenges were technological (broadband internet access, older devices). When asked what they liked most, one PLWD said: "BEING AT HOME! We try to get out as much as possible but getting ready to go out, going out and coming home takes a lot of energy and we are not sure we would participate if it were not online."

Out-of-Pocket Costs for Dementia: A Longitudinal Perspective

Author: **Melissa Oney**

We estimate the out-of-pocket (OOP) costs of dementia, by gender and race/ethnicity, to estimate the financial burden arising from a gap in insurance coverage for long-term care created by Medicaid and Medicare. The incremental OOP cost of AD/DRD is \$7,586 per patient over the first 8 years of onset, equivalent to almost half the costs to Medicare. OOP spending is decreasing over this period, consistent with trends in Medicare expenditures. Nursing homes comprise the largest component of OOP spending, and are a major driver of differences in OOP spending by gender and race/ethnicity. The gap in insurance coverage leaves a large financial burden on those with dementia, particularly for minorities. Limited access to resources may reduce OOP expenditures by limiting the use of formal care. Because these costs reflect formal care only, inclusion of informal care costs may paint a very different picture of the burden of costs.

Pre-loss Group Therapy for Family Caregivers at Risk for Complicated Grief

Authors: **Kathie Supiano, Troy Andersen, and Cynthia Beynon**

We adapted our Complicated Grief Group Therapy into a manualized preventative approach—Pre-Loss Group Therapy (PLGT)—for family caregivers at risk for complicated grief. We implemented and evaluated three PLGT cohorts in three nursing homes with family caregivers at-risk for complicated grief whose care recipient had a life expectancy of 6 months or less and resided in a long-term care facility. Preliminary evaluation of preparedness, self-care and grief outcomes shows significant improvement across domains and we are presently awaiting post-death data on some participants. We evaluated early stage intervention feasibility components of recruitment, retention, treatment fidelity; and PLGT participant acceptability, tolerability, satisfaction, and treatment adherence. Feasibility targets were achieved. We recruited and trained two long-term care facility licensed clinical social workers to implement PLGT in their facilities and are presently evaluating PLGT participant change processes, preparedness, self-care and grief outcomes, as well as social worker treatment fidelity, skill performance, and satisfaction.

*Priorities and Concerns of Older Latinos Living Alone with Cognitive Impairment: An In-Depth Perspective

Authors: **Elizabeth Rivera**, J.K. Johnson, K.E. Covinsky, S. Keiser, J. Ortez-Alfaro, M. Barrientos, and E. Portacolone

Older Latinos are 1.5 times as likely as Whites to have cognitive impairment (CI) with 1/3 of older adults with CI living alone in the U.S. There is limited knowledge about the priorities and concerns of older Latinos living alone. Method: Ethnographic interviews and participant observation were used to elicit priorities and concerns of older Latinos living alone with CI. Interview and fieldnotes scripts were analyzed utilizing a qualitative content analysis approach. Themes found priorities to be: 1) Engaging with community; 2) Maintaining dignity; 3) Access to services. Concerns included: 1) Conflictual relationships; 2) Limited appropriate services available; 3) Difficulty managing affairs; 4) Limited understanding of CI. Findings highlight the challenges to access services were compounded by a desire for maintaining dignity and limited support from family members, as well as immigration status and language barriers. Future research is needed to identify specific priorities and concerns related to service utilization and race/ethnicity.

Race Differences in Trends in Dementia Family Care Through 2060

Author: **Esther Friedman**

Alzheimer's disease and related dementias are among the costliest health conditions in America, with most of the costs coming from long-term services and supports, such as bathing, dressing, and mobility – much of which is provided by family. Demographic changes, such as lower fertility, could suggest that there may not be enough close kin to meet the needs of adults with dementia in the future. To examine this, we link a demographic kinship model with a model of dementia incidence and estimate the future availability of close kin to adults with dementia through 2060. This work suggests that white women with dementia will show the steepest increases in kinlessness, nearly matching the levels of black women by 2035. Among people without dementia, we expect an increase in time spent “at risk” of being a dementia caregiver. We will also describe the demographic mechanisms underlying race and gender differences in these trends.

STAR-Caregivers Virtual Training and Follow-up: Pragmatic Trial Protocol

Author: **Robert Penfold**

Behavioral and psychological symptoms of dementia (BPSD) are common and often involve aggressive behavior towards family caregivers. BPSD are disturbing and frequently lead to caregivers seeking medication to control patient symptoms. Antipsychotic use in persons with dementia more than doubles mortality risk. The STAR-Caregivers program is an education and support intervention demonstrated efficacious in reducing BPSD. However, the program has not been implemented widely – partly due to the cost of the programs, difficulty conducting outreach, and modality of training (in person). We are conducting a pragmatic clinical trial to ascertain the efficacy of a scalable version of STAR-C in which caregivers (a) learn online (b) have an in-home visit with a social worker and (c) receive ongoing support via telephone and email. This poster describes the trial protocol and issues related to recruiting and consenting/assenting caregiver-patient dyads.

State Assisted Living Regulations and Cognitive Screening at Admission

Authors: **Taylor Bucy and Paula Carder**

Roughly one million people live in assisted living (AL) settings, and 40 to 72 percent have AD/ADRD or are cognitively impaired. Pre-admission assessment for dementia or cognitive impairment can facilitate appropriate health service planning. Despite agreement by federal, state, and private organizations regarding the importance of cognitive impairment screening for individuals as they age, only about half of persons 65-years and older receive cognitive assessments. This study of how states regulate dementia care in AL (R01AG057746), examined state requirements for cognitive screening in all 50 states and DC over a 12-year period (2007-2018). Between 2007 and 2018, 18 states implemented policies requiring cognitive impairment screening at admission for AL settings. This poster compares states that require standard assessment tools to states with general admission criteria policies. These results may be linked to resident-level health service use to analyze variability in resident outcomes across states.

***State Variability in Dementia Diagnosis Prevalence and Medicare Expenditures Across the U.S.**

Author: **Emmanuel Fulgence Drabo**

National estimates of AD/DRD prevalence mask potential state variations in rates. Accurate state-level estimates of AD/DRD prevalence are critical to assessing the current and future burden of AD/DRD for states particularly costs associated with LTSS. Using claims data for a 20 percent sample of older adult Medicare beneficiaries (67+y; n = 3,845,174), we characterized State variability in AD/DRD diagnosis prevalence and Medicare expenditures. Results suggest variations in AD/DRD prevalence across states (SD, 3.3 percent), with rates highest in Connecticut (12.8 percent) and lowest in Alaska (5.0 percent). Medicare expenditures among all beneficiaries also varied across states, ranging between \$11,997 in Hawaii and \$16,971 in New York. Expenditures among individuals with AD/DRD were double and accounted for 68 percent of the variation in expenditures by all beneficiaries. These findings suggest that States with a greater concentration of individuals at risk of AD/DRD may become increasingly exposed to the burden of AD/DRD.

The Impact of Patient Dementia Status on Family Caregiver Assistance and Resource Utilization during Medicare Home Health Care

Author: **Julia Burgdorf**

This study compares the type and intensity of home health visits and the need for family caregiver assistance during home health by dementia status among Medicare beneficiaries. We draw from linked nationally representative survey data from the National Health and Aging Trends Study (NHATS), clinical assessments during home health from the Outcome and Assessment Information Set (OASIS), and Medicare claims data for a nationally representative sample of Medicare beneficiaries who experienced at least one home health episode between 2011-2016. We find that those with dementia were significantly more likely to require family caregiver assistance during home health across a number of caregiving tasks and incurred significantly more nursing, therapy, and personal care aide visits during home health. Findings highlight the importance of targeted supports for family caregivers of those with dementia and point to a need to account for patient dementia status when considering future home health payment system changes.

The Pain Identification and Communication Toolkit (PICT): A Novel Intervention to Help Family Caregivers of Persons with Dementia Recognize and Communicate about Pain

Author: **Catherine Riffin**

This presentation will describe the approach to developing, refining, and pilot testing the Pain Identification and Communication Toolkit (PICT), a novel intervention to help family caregivers recognize pain symptoms in persons with dementia and communicate those symptoms to health care providers. The poster will delineate the components of the PICT intervention manual, including modules that prepare caregivers to: a) recognize and differentiate pain from dementia symptoms, b) administer an observational pain assessment tool, c) communicate effectively about pain symptoms, and d) plan steps to take when pain is detected. It will also report results from the process by which preliminary versions of the PICT manual were refined, and describe an ongoing pilot randomized controlled trial evaluating the acceptability, feasibility, and potential impact on caregivers' initiation of pain-related communication with health care providers. Future directions will also be discussed, including plans for the dissemination and implementation of PICT in medical and community-based settings.

The Role of Paid Caregivers in Home-Based Dementia Care

Author: **Jennifer M. Reckrey**

As care needs of those with dementia grow, family caregivers may turn to paid caregivers (e.g., home health aides, personal care attendants) for additional support. We used semi-structured interviews with patients, family caregivers, and paid caregivers to explore the tasks paid caregivers perform and how paid caregivers communicate with family caregivers and health care providers. Paid caregivers performed a wide variety of health-related tasks, but they deferred to family caregivers to decide when and how they interacted with health care providers. Close relationships enhanced communication. Paid caregivers are intimately involved in the care in the home and have the potential to positively impact both the older adults they care for and the families with whom they share care. Future work will use both quantitative and qualitative approaches to better understand how family caregivers and paid caregivers work together to provide the comprehensive care that keeps older adults with dementia living at home.

*Uncovering Dementia Care Partner Gaps of Knowledge of Medical Management

Authors: **Tatiana Sadak** and Soo Borson

Improving the health of people living with dementia (PLWD) is a priority for health care redesign and reducing need for hospitalization, with its attendant risks. Understanding care partners' (CPs') knowledge of medical management and prognosis is important for clinical crisis prevention research and innovation. We evaluated 100 CPs of recently hospitalized PLWD with moderate to severe dementia, using CP interviews and measures and PLWD medical records. CP reported that clinicians had not disclosed a dementia diagnosis to them (29 percent) or discussed prognosis (84 percent) or helped them weigh the pros/cons of hospitalization (76 percent). Eighty three percent of CPs had gaps in objective knowledge of PLWDs' chronic conditions and/or medications but perceived their knowledge as good. Potential predictors of knowledge gaps included CP cognitive impairment and demographic characteristics. Further work is needed to mitigate these knowledge gaps and improve CP-provider communication to optimize health care of PLWD.

*Understanding the Experience of Persons Living with Dementia and their Care Partners in a Memory Café Style Program: A Qualitative Multi-Stakeholder Analysis

Author: **Inga Antonsdottir**

Memory cafés and similar programs are an emerging community-based strategy to support persons living with dementia and their caregivers, yet little is known about their impact or how they work best. Using qualitative methods, we investigated the perceived impact, benefits, and weaknesses of the Club Memory® at Sibley Memorial Hospital from a multiple stakeholder perspective. Focus groups revealed congruent perspectives of how the program is perceived by program recipients living with dementia and caregivers and opportunities for improvement. Major themes of the program's strengths included: Atmosphere, Sense of Community, Skill-Building, Tools, and Strength in Staff. Memory café-style programs like Club Memory® appear to be a valuable community-based program that creates a stigma-free supportive environment to educate and support program recipients. Our findings contribute to a deeper understanding of members' experience in Club Memory® and how this program might be improved and standardized for dissemination and broader implementation.

Using Participatory Design and Community Engagement to Develop Online Caregiver Support

Author: **Rebecca Utz**

We used participatory design and community engagement when developing an online intervention to support family caregivers to persons with AD/DRD. Each Community Advisory Board member was asked to 1) provide their own story (narratives) which allowed us to better understand stakeholder needs and wants, 2) to create, which allowed them to generate ideas and create specific content for the intervention, 3) to prioritize which features ought to be included in the intervention tools, oftentimes requiring us to compromise between ideal content and feasible content, and 4) to contextualize how the intervention might be adopted in real life and applicable to diverse individuals and communities. By seeking and then authentically applying stakeholder input from the earliest stages of conceptualization through the development of the online tools and content, we believe we have enhanced the translation and scalability of the intervention to real world practice and utility.

Using the Emergency Department for Cognitive Screening: Assessing Downstream Impacts on the Health Care System

Author: **Walter Dawson**

Fifty percent of people living with AD/DRD never receive a formal diagnosis. This compromises the well-being of persons living with AD/DRD and caregivers and increases health services utilization and costs. Wider AD/DRD screening may increase access to supportive care, improve medical care allocation, and foster interventions that prevent or delay disease progression. This pilot study administers the cognitive General Practitioner Assessment of Cognition (GPCOG) in digital format to 120 Medicare enrolled adults 65+ presenting to an emergency department (ED) in Portland, Oregon. The screen is supplemented by the GPCOG Informant Interview. Follow up one-week post-discharge from the ED will occur via the Telephone Interview for Cognitive Status to confirm results. This pilot is proof of concept for using an ED to administer cognitive screening, linking outcomes to the EHR, and provides a platform for further research on undiagnosed AD/DRD's impact on outcomes and utilization amongst vulnerable populations.

What Do I Really Need? Assessment of Caregiver Supports for People with Intellectual and Developmental Disability and Dementia

Author: **Kathryn Service**

People with intellectual and developmental disability (IDD) experience complex age-related issues, including dementia-related disorders, frequently at higher rates and at earlier ages than the general population. The resulting increased needs can strain existing support systems, particularly caregivers of this population. A focused needs assessment of 95 such caregivers measured whether they had received any dementia care training, care confidence levels, perceived barriers to care and knowledge of aging resources. The 54 home visits included an environmental assessment. Caregivers noticed a significant change in functional skills, memory, and affect since diagnosis of dementia for this person they support. Most frequent concerns included lack of suitable day programming, planning for the person's future, and caregiver burnout and stress. Most caregivers were aware of community aging resources but used them infrequently. Homes, while accessible, warranted additional lighting and clutter removal. Respondents found the interviews with the Nurse Practitioner helpful, but many requested additional training for behavioral distress.

***What Does it Take? Reaching Hispanic/Latino and Black/African American Dementia Caregivers in Community-Based Research**

Authors: **Lauren J. Parker** and Laura N. Gitlin

While Hispanic/Latino and Black/African Americans are at increased risk for Alzheimer's disease, often they are cited as a "difficult-to-reach population" to engage in community-based research or clinical trials. Strategic priorities of the NIA's National Strategy for Recruitment and Participation in Alzheimer's and Related Dementias Clinical Research are to increase awareness and engagement and to support participants. Leveraging the recruitment strategies from two NIA-funded dementia caregiving research studies, ADS-Plus and The Providing Evidence-Based Approaches to Caregiver Stress (PEACE Study), the goal of this poster is to discuss approaches to developing culturally relevant recruitment strategies. Recruitment strategies from the two studies will explore the impact of race/ethnicity on recruiting Hispanic (ADS-Plus), and Black/African Americans (PEACE Study) populations. Further, the effectiveness of recruitment strategies from both studies will be discussed, to (1) conceptualize best practices necessary to develop and sustain equitable and sustainable community partnership, and (2) create and improve evidence-based recruitment resources.

Variation in Family and Friend Caregiving of Community-Dwelling Persons with Dementia: From Incidence to 6 Years Post Onset

Authors: **Eric Jutkowitz, Lauren L. Mitchell, Amal Trivedi, Pedro Gozalo, and Joseph E. Gaugler**

People living with AD/ADRD receive support from family and friend caregivers. Yet, little is known about how time spent caregiving and caregiving arrangements evolve over the disease. We used data from the NIA-funded Health and Retirement Study and latent class analysis to determine the variation in the amount of family/friend caregiving received by people with AD/ADRD from disease onset up to 6 years post onset. Community-dwelling people with AD/ADRD receive a large amount of care over the first 6 years following disease onset, and there is heterogeneity in the organization of caregivers. The latent class analysis identified two distinct caregiving arrangements. In the first group, persons with AD/ADRD received an overwhelming majority of care from a spouse. In the second group, persons with AD/ADRD received care from multiple care partners (e.g., spouse and children). The referral/delivery characteristics of services/supports for people with AD/ADRD must account for diverse caregiving arrangements.

INFORMATIONAL POSTERS

Adult Day Services: More than Just “Dancing and Dominoes”

Author: **Tina Sadarangani**

Adult day service centers (ADCs) are essential community resources that often allow frail older adults to avoid institutional care. Once belittled as a place for older adults to “dance and play dominoes,” ADCs are increasingly providing comprehensive care, chronic disease management, and specialized programs for persons with AD/ADRD. They also engage in developing and implementing evidenced-based models of dementia care for patients and caregivers. In recent years, there has been a surge in research-related activities within the ADC community, as well as through collaborations with academic and government institutions. The National Adult Day Services Association Research Committee serves as an information source for researchers, patients, and caregivers seeking to engage in research surrounding management of dementia and other chronic diseases. The purpose of this poster is to increase awareness of the comprehensive services provided within ADCs as well as research currently taking place.

Advancing the Delivery of Dementia Care, Services, and Supports: Examples of Cross-Cutting, High-impact Dementia Research Methods

Authors: **Heather Menne, Sari Shuman, Elizabeth Gould, Sarita Karon, Stephanie Hughes, Zhanlian Feng, and Edith Walsh**

To advance the real-world delivery of dementia care, services, and supports, there is a need for cross-cutting, high-impact dementia research using a broad range of methods (e.g., instrument development, synthesis of existing resources, analysis of survey and administrative health care data). RTI's dementia experts work to apply the most appropriate methods to address the ongoing and emerging issues challenging the field of dementia care. This poster highlights selected research activities undertaken by RTI's dementia experts to advance dementia care, services, and supports.

Demography of Dementia and Dementia Caregiving

Authors: **Mark Mather and Paola Scommegna**

Dementia is one of the nation's most expensive old-age health conditions and the most time consuming for family caregivers. There are nearly 6 million people ages 65 and older living with AD/ADRD in the United States, representing about 1 in 10 older Americans. However, rates of dementia are not uniform across the older population. Racial/ethnic minorities, women, the oldest old, and those with less education are at greater risk of dementia. Living arrangements of people with dementia—whether they live in the community, residential care facilities, or nursing homes—also differ depending on the availability of family caregivers and financial resources. This poster summarizes what we know about the characteristics of people with dementia and their caregiving and living arrangements. Understanding the characteristics of those with dementia can help lawmakers design policies that better meet the needs of this rapidly growing population and their families.

New Data on Senior Care Housing: NIC-MAP

Author: **Emily Blecker**

This poster provides information on the National Investment Center for Seniors Housing & Care's NIC-MAP database, the most comprehensive database available on senior care housing. The NIC-MAP contains data on market-rate independent living, assisted living, continuing care retirement communities, memory care, and nursing care properties located in the 100 largest U.S. metro markets. NIC-MAP data are collected annually at the community-level and are linked across years to identify expansions and new construction. We outline the steps on gaining access to this database, the potential uses for the NIC-MAP data, and a few maps highlighting the breadth and depth of information in this database. One map shows summary level information on the locations of senior care facilities in the NIC-MAP database; another map shows regional growth in the types of housing over time. We highlight the community-level variables available, allowing researchers to identify their own potential uses using the NIC-MAP data for their own analyses.

Supporting Dementia Friendly Communities Across the US

Authors: **Meredith Hanley and Brenda Luna Macedo**

Dementia Friendly America (DFA) is a national collaborative working to advance dementia friendly communities across the United States. A dementia friendly community is a village, town, city or county that is informed, safe and respectful of people with dementia, their families and caregivers and provides supportive options that foster quality of life. DFA helps to foster local community transformation through its Community Toolkit, designed to guide communities through a process of becoming more dementia friendly. DFA launched in 2015 and is based upon Minnesota's successful statewide initiative, ACT on Alzheimer's. DFA is also the U.S. licensee of Dementia Friend, an international public awareness campaign, which works on a more micro scale to give people an understanding of dementia and how everyone can make a difference. From helping someone find the right bus, to spreading the word about dementia - individuals are empowered by knowing that every action counts.

The Integrated Memory Care Clinic's New Model of Care: Comprehensive Primary and Dementia Care

Authors: **Carolyn K. Clevenger and Laura Medders**

The Integrated Memory Clinic (IMCC) is the nation's first and only comprehensive primary and dementia care practice. The IMCC model addresses the conundrum confronting almost all of the country's 5.8 million individuals living with dementia: How to overcome the challenge of identifying a primary care practice that is knowledgeable about, and sensitive to, the complex medical and social issues associated with a dementia diagnosis and that can also manage the co-morbidities common in aging. The IMCC's patient-centered approach allows patients to receive an array of health care services in a single visit. Nurse practitioners, geriatricians, neurologists, social workers, and medical assistants provide exemplary care coordination in all areas of the patient's care. Whether the patient with dementia has a cold, is due for a vaccination, or experiences a change in behavior, clinic care services are available 24/7 through in-person same-day clinic visits or round-the-clock access to a team of dedicated providers.

The Memory Farm®: An Innovative and Evidence-Based Model of Non-Residential Dementia Care for Underserved Communities

Authors: **Johanna C. Jameson, Agnes L. Becker, and Debra A. Fleischman**

Identifying new models of delivering non-residential services is an important theme of the NIA Dementia Care Summit 2020. A new concept in adult day care, The Memory Farm, is described here. The primary mission of the Memory Farm is to bring purpose, dignity and well-being to people living with dementia through compassionate, farm-based activities. Many persons with early stage cognitive impairment remain physically strong and want to stay active but need supervision and do not fit the traditional model of adult day care. The Memory Farm offers this under-served group an opportunity to be physically, cognitively and socially active through purposeful work in a nature setting. The mission extends to care partner support through education, respite, and social activities, to the community through educational events that reduce the stigma of cognitive impairment, and to the next generation of dementia care providers by partnering with academic institutions to provide student mentoring.

The National Health and Aging Trends Study and the National Study of Caregiving

Authors: **Vicki Freedman, Judy Kasper, and Jennifer Wolff**

Since 2011, the National Health and Aging Trends Study (NHATS) has collected detailed information annually about the disability and care needs of a panel of over 8,000 older adults (with periodic sample refreshments in 2015 and 2020). NHATS collects a wide array of data on older adults, including cognitive assessments that allow identification of probable dementia. The National Study of Caregiving (NSOC) provides nationally representative data on family and unpaid caregivers to older adults obtained through interviews with persons who provide assistance to NHATS participants. NSOC has been conducted periodically (2011, 2015, 2017) and starting in 2020 will be conducted annually in concert with NHATS. This poster will describe: 1) the design of the NHATS and NSOC, 2) key findings related to dementia care, 3) Medicare and geographic linkages that are available to the research community, and 4) information about the process for accessing public use files, sensitive files, and restricted data linkages.

The UCLA Alzheimer's and Dementia Care Program: An Innovative Nurse Practitioner-Led, Health System-Based Model of Comprehensive Dementia Care

Author: **Kemi Reeves**

The UCLA Alzheimer's and Dementia Care Program provides patient-centered, comprehensive dementia care management with primary goals to maximize patient function and dignity, minimize caregiver strain, and reduce unnecessary health care cost. The Program is a collaborative practice in which patients retain their primary care provider while a nurse practitioner Dementia Care Specialist provides dementia care for patients and their families. The Program has benefitted patients with dementia by addressing critical health care, social services, and family caregiver needs while improving health outcomes and lowering health care costs. Based on the UCLA experience, implementing the Program has led to 92 percent of quality indicators for dementia care being met, 96 percent of caregivers reporting that they felt supported, 40 percent reduction in long-term nursing home placement, and \$2,404 savings per participant per year in Medicare costs.

The University of South Carolina, Arnold School of Public Health, Office for the Study of Aging and its Approach to Disseminating Information, Education, and Research on Aging

Authors: **Stephanie Ureña, Katherine Leith, Megan Byers, and Maggi Miller**

South Carolina is among the top ten states with the fastest growing population of older adults, and approximately 93,000 South Carolinians are living with AD/ADRD. The University of South Carolina Arnold School of Public Health's Office for the Study of Aging's core mission is to prepare South Carolina to meet the needs of a growing older adult population and to enhance the quality of life for these individuals as they age. To fulfill its mission, OSA (a) houses the South Carolina Alzheimer's Disease Registry, one of only three AD/ADRD registries in the nation, (b) supports the Certificate of Graduate Study in Aging, a post-bachelor's program to obtain specialized preparation for careers in aging, and (c) implements the nationally registered Dementia Dialogues® program, a 5-module training designed to educate the community and individuals who care for persons who exhibit signs and symptoms of AD/ADRD.

Visual Mapping Assistive Technology Can Help Individuals with Dementia and their Caregivers Successfully Complete Activities of Daily Living and Enhance Quality of Life

Author: **Matthew Golden**

The MapHabit™ system is personalized mapping software for mobile devices that is safe, noninvasive, and low cost. Using MapHabit, memory-impaired individuals and their caregivers can create personalized visual maps that lay out the sequential steps for accomplishing activities of daily living (ADLs) and other activities. In addition, using visual maps, overall quality of life and independence can be enhanced both for memory-impaired individuals and their caregivers. MapHabit is exceptionally user-friendly and accessible on many consumer-technology devices. An innovative neuroscience component of MapHabit is its focus on neostriatal regions of the brain involved with procedural (habit) memory. These regions can be less affected than other brain regions by the pathology of Alzheimer's disease, and we take advantage of that sparing by using visual maps that reinforce routine behaviors (habits) linked to the individual's ADLs. Additionally, caregivers can track ADLs and other activities and monitor adherence to medications and other schedules.



SUMMIT STAKEHOLDER GROUPS

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Alzheimer's Family Support Program

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**RESEARCH SUMMIT ON
DEMENTIA CARE**
Building Evidence for Services and Supports

The logo for the Research Summit on Dementia Care features a vertical column of six small icons: a person, a brain, a gear, a house, a person with a speech bubble, and a person with a speech bubble. The text "RESEARCH SUMMIT ON" is in white, "DEMENTIA CARE" is in large orange letters, and "Building Evidence for Services and Supports" is in white below it.