

2023 NATIONAL RESEARCH SUMMIT ON

# Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers

**Summit Virtual Meeting Series**

March 20-22, 2023

National Institute on Aging, National Institutes of Health



National Institute on Aging

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## Summit Goal

The 2023 Dementia Care and Caregiving Research Summit will build on progress of the previous Summits to review research progress, highlight innovative and promising research, and identify remaining unmet research needs with input from the research community, persons living with dementia (PLWD) and their care partners, those who provide health care or services and supports to PLWD, and other stakeholders. The summit will be held virtually on March 20-22, 2023.

## About the Dementia Care and Caregiving Research Summit

The National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers (Dementia Care and Caregiving Research Summit), the [Alzheimer's Research Summits](#), and the [Alzheimer's Disease-Related Dementia Summits](#) provide coordinated planning efforts that respond to the [National Plan to Address Alzheimer's Disease](#). Each summit provides an opportunity for individuals to share perspectives about critical scientific gaps and opportunities that reflect critical scientific priorities for Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) research. The summits can inform updates to the [NIH AD+ADRD Research Implementation Milestones](#) that address the National Plan.

The first [National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers](#) was held on the NIH campus on October 16-17, 2017. The second [care-focused summit](#) was held virtually in the summer of 2020.

## 2023 Summit Cross-Cutting Themes

- Inclusive science and health equity
- What matters framework
- Rigor and reproducibility of dementia care research

## Summit Steering Committee Members

### Co-Chairs

**Andrea Gilmore-Bykovskyi**, University of Wisconsin

**Julie Zissimopoulos**, University of Southern California

### Committee Members

**Antonia V. Bennett**, University of North Carolina  
Chapel Hill

**Basil Eldadah**, National Institute on Aging

**Cerise Elliott**, National Institute on Aging

**Chanee Fabius**, Johns Hopkins University

**Elena Fazio**, National Institute on Aging

**Melissa Gerald**, National Institute on Aging

**Crystal M. Glover**, Rush University

**Kenneth W. Hepburn**, Emory University

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

**Pei-Jung Lin**, Tufts University

**Luis D. Medina**, University of Houston

**Liz Necka**, National Institute on Aging

**Emerald T. Nguyen**, National Institute on Aging

**Priscilla Novak**, National Institute on Aging

**Katherine Possin**, University of California  
San Francisco

**Marcel Salive**, National Institute on Aging

**Joanne Spetz**, University of California San Francisco

**Luke Stoeckel**, National Institute on Aging

### Summit Core Planning Team

**Jessica Boten**

**Elena Fazio**

**Chandra Keller**

**Nicole Kidwiler**

The development and hosting of the 2023 Dementia Care and Caregiving Research Summit was supported by Rose Li & Associates, Inc.



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## About the Dementia Care and Caregiving Research Summit

The National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers (Dementia Care and Caregiving Research Summit), the [Alzheimer's Research Summits](#), and the [Alzheimer's Disease-Related Dementia Summits](#) provide coordinated planning efforts that respond to the [National Plan to Address Alzheimer's Disease](#). Each summit provides an opportunity for individuals to share perspectives about critical scientific gaps and opportunities that reflect critical scientific priorities for Alzheimer's disease and Alzheimer's disease related dementias (AD/ADRD) research.

The first [National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers](#) was held on the NIH campus on October 16-17, 2017. The second [care-focused summit](#) was held virtually in the summer of 2020.

### Summit Virtual Meeting Series Dates

March 20, 2023, 11:00 a.m. – 4:00 p.m. EDT

March 21, 2023, 11:00 a.m. – 3:30 p.m. EDT

March 22, 2023, 11:00 a.m. – 3:45 p.m. EDT



Visit the [2023 Summit website](#) for the most up-to-date information.

### 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

### Session 1: What Matters Framework and Living Well with AD/DRD

*Session Co-Chairs: Antonia V. Bennett and Basil Eldadah*

This session will include considerations of outcomes that matter most to persons living with dementia (PLWD) and their care partners (e.g., Jessen et al., 2022) and models for living well with dementia (e.g., UK national strategy, dementia-friendly communities). Research presentations may consider lessons learned from international settings that can be applied to the U.S. context and implications for future research. The session can include international exemplars, approaches to measuring outcomes in care and caregiving research, data or other research infrastructure needs, and the importance of including positive outcome measures in research. Presenters include Siobhan Reilly, Sheila L. Molony, and Lee A. Jennings.

### Session 2: Impact of Detection and Diagnosis on Individuals and Care Partners

*Session Co-Chairs: Luis D. Medina and Luke Stoeckel*

This session will address approaches to early and equitable detection of dementia as an entry point into dementia care and will consider the social, economic, and institutional barriers to and facilitators of detection and diagnosis within care settings, including in primary care and in the context of the Medicare annual wellness visit. Research presentations may consider the impact of detection and diagnosis on individuals and families across diverse contexts and backgrounds. Presentations may also address issues of communicating a diagnosis and ethics of disclosure. Presenters include Raj C. Shah, Ellen McCreedy, and Emmanuel Fulgence Drabo.

### Session 3: Dementia Care Models and Coordination of Care

*Session Co-Chairs: Katherine Possin and Marcel Salive*

Dementia care models and coordination of care are complex and involve a multilevel framework that includes individual and family, community, policy, and societal levels. Care is provided and received in a variety of health and community-based care settings with varying levels and types of resources at differing stages of disease, including end-of-life. This session will explore community- and health system-based dementia care model exemplars as well as the inherent challenges in developing and disseminating evidence-based models of integrated care in real-world settings to meet the diverse needs of PLWD. Research presentations may address care models, transitions in care, considerations that operate across the continuum of care needs from diagnosis to end-of-life, and/or payment models that facilitate comprehensive, collaborative dementia care. Presenters include Eric B. Larson, David B. Reuben, and Ula Hwang.

### Session 4: Disparities in Health Care Access, Utilization, and Quality

*Session Co-Chairs: Chanee Fabius and Emerald T. Nguyen*

This session will consider the policies, health care structures and practices, neighborhood, and social and economic factors that impact health equity in care access, use, care transitions, and quality of care. It may consider both health care services and specific medical treatment and management approaches. Research presentations may include notable changes in policy (e.g., telehealth) affecting care and consider priority research and infrastructure needs to address structural racism and other drivers of disparities among minoritized populations, including attention to indigenous populations and approaches to research. Presenters include Shekinah Fashaw-Walters, Jie Chen, and Norma B. Coe.

## Session 5: Support for Care Partners and Caregivers

*Session Co-Chairs: Kenneth W. Hepburn and Liz Necka*

This session will explore caregiving needs, supports, and sources of strength and resilience, which can vary by culture, caregiving networks, stage of disease, and living situation (e.g., kinlessness, PLWD living alone). Topics may also include factors that facilitate or impede the uptake of caregiver-friendly policies and practices in health care and workplace settings. Presentations may address cultural considerations in appraisal of caregiving roles and supports at individual, familial, and system levels. Presentations highlighting innovative caregiver focused behavioral interventions should identify the targets and mechanisms of action of the intervention. Presenters include Karen A. Roberto, Joseph E. Gaugler, and Courtney Van Houtven.

## Session 6: Dementia Care Workforce

*Session Co-Chairs: Joanne Spetz and Elena Fazio*

This session will explore research innovations and challenges pertaining to the paid dementia care workforce across a range of settings, including clinical care, nursing homes, assisted living, and home- and community-based services settings. Findings relevant to the dementia care workforce from the 2022 National Academies of Sciences, Engineering, and Medicine (NASEM) consensus study report *The National Imperative to Improve Nursing Home Quality* and implications for future research as well as workforce needs to support innovations for PLWD and care partners in the community will be explored. Presenters include Bianca K. Frogner, Jasmine L. Travers, and Jennifer M. Reckrey.

## Session 7: Economic Impacts, Implications, and Approaches

*Session Co-Chairs: Pei-Jung Lin and Priscilla Novak*

This session will discuss the economic impact of dementia on families and the health care system and opportunities to alleviate economic burden. Presentations will consider financial incentives in the health care system to improve dementia care coordination and patient outcomes and to reduce costs. They will also address novel approaches to measuring the value of innovations in dementia care and treatment, and the impact of dementia on health care and economic decision making. Presenters include Duke Han, Mireille Jacobson, and Peter J. Neumann.

## Session 8: Approaches to Participatory Research and Diverse Recruitment and Retention in Dementia Care Research

*Session Co-Chairs: Crystal M. Glover and Cerise Elliott*

This session will explore a range of topics related to the practice of scientific inclusion in dementia care/caregiving research across diverse contexts and populations. Presentations will highlight participant-centered and community-based approaches to equitable study design with a focus on outreach, engagement, recruitment, and sustainability. Presenters will explore diversity within diversity as it pertains to addressing challenges and amplifying facilitators of equitable study design and emergent practices for promoting inclusion in the context of caregivers and care recipients who have been under-included in research. Presenters include Jordan P. Lewis, Van Ta Park, and Fayron Epps.

## **Plenary Talk: Challenges and Best Practices for Dissemination and Implementation of Interventions for Persons Living with Dementia and their Care Partners**

Recent key reports (e.g., Agency for Healthcare Research and Quality [AHRQ] systematic review and NASEM care interventions report) have noted that behavioral interventions for PLWD and/or their caregivers for which research evidence demonstrates the integral components that drive behavior change and make the intervention successful are lacking. This can be a roadblock to building a cumulative science and widespread dissemination in practice. This plenary talk will highlight opportunities for improving the rigor, reproducibility, and dissemination potential of intervention research. The plenary presentation will be given by Linda M. Collins.

## Meeting Agenda

### DAY 1: MARCH 20, 2023

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11:00 a.m. – 12:00 p.m. ET:

#### Setting the Stage

11:00 a.m. – 11:15 a.m. ET: Welcome and Meeting Charge

Speakers: **Andrea Gilmore-Bykovskyi** and **Julie Zissimopoulos**

11:15 a.m. – 11:30 a.m. ET: Lived Experience Panel and Stakeholder Panel Highlights

Speakers: **Les Burger**, **Gary Epstein-Lubow**, **Reda Harrison**, and **Monica Moreno**

11:30 a.m. – 11:35 a.m. ET: NIA Welcome

Speaker: **Amy Kelley**

11:35 a.m. – 12:00 p.m. ET: NIA Dementia Care and Caregiving Research

Speaker: **Elena Fazio**

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12:00 p.m. – 1:05 p.m. ET:

#### Session 1 | What Matters Framework and Living Well with AD/ADRD

*Session Co-chairs: Antonia V. Bennett and Basil Eldadah*

What Matters to People Living with Dementia Living at Home? Developing Outcomes and the Evidence Base When Evaluating Interventions

Speaker: **Siobhan Reilly**

Observable Expressions of Positive and Negative Emotion: Affect-Balance

Speaker: **Sheila L. Molony**

Personalized Health Outcome Measurement in Dementia Care and Services Research

Speaker: **Lee A. Jennings**

Session 1 Research Gaps and Opportunities

Speaker: **Antonia V. Bennett**

Panelist Remarks

Speakers: **Emmanuelle Belanger**, **Sam Fazio**, and **Jim Mangi**

Moderated Discussion and Q&A

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1:05 p.m. – 1:45 p.m. ET: **Lunch Break**

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1:45 p.m. – 2:50 p.m. ET:

**Session 2 | Impact of Detection and Diagnosis on Individuals and Care Partners**

*Session Co-Chairs: Luis D. Medina and Luke Stoeckel*

Risk Prediction of Alzheimer’s Disease and Related Dementias in Primary Care Settings

Speaker: **Raj C. Shah**

Challenges to Equitable Identification of People Living with Dementia for Pragmatic Clinical Trials

Speaker: **Ellen McCreedy**

Disparities and Challenges in Dementia Care after Diagnosis

Speaker: **Emmanuel Fulgence Drabo**

Session 2 Research Gaps and Opportunities

Speaker: **Luis D. Medina**

Panelist Remarks

Speakers: **Nate Chin**, **Deborah Jobe**, and **Emily Largent**

Moderated Discussion and Q&A

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2:50 p.m. – 3:50 p.m. ET:

**Plenary Talk | Challenges and Best Practices for Development and Evaluation of Interventions for Persons Living with Dementia and Their Care Partners**

Speaker: **Linda M. Collins**

Moderated Discussion and Q&A

Moderator: **Lisa Onken**

Speakers: **Kathi Heffner**, **Brent Mausbach**, and **Christina S. McCrae**

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3:50 p.m. – 4:00 p.m. ET:

**Day 1 Closing Remarks**

Speakers: **Andrea Gilmore-Bykovskyi** and **Julie Zissimopoulos**

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4:00 p.m. ET: **Day 1 Adjourn**

## DAY 2: MARCH 21, 2023

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11:00 a.m. – 11:05 a.m. ET: Welcome

Speakers: **Andrea Gilmore-Bykovskyi** and **Julie Zissimopoulos**

11:05 a.m. – 11:20 a.m. ET: Lived Experience Panel and Stakeholder Panel Highlights

Speakers: **Roberta Cruz**, **Heidi Gil**, and **Ian Kremer**

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11:20 a.m. – 12:25 p.m. ET:

### Session 3 | Dementia Care Models and Coordination of Care

*Session Co-chairs: Katherine Possin and Marcel Salive*

The NASEM Report: Rationale, Illustrative Findings and Expectations of a Way Forward

Speaker: **Eric B. Larson**

The Vanguard of Comprehensive Dementia Care: Much Done, Much More to Do

Speaker: **David B. Reuben**

Dementia in the Acute Setting: Expanding and Improving Care

Speaker: **Ula Hwang**

Session 3 Research Gaps and Opportunities

Speaker: **Katherine Possin**

Panelist Remarks

Speakers: **Carolyn Clevenger**, **Roberta Cruz**, and **Shari M. Ling**

Moderated Discussion and Q&A

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12:25 p.m. – 1:00 p.m. ET: **Lunch Break**

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1:00 p.m. – 2:05 p.m. ET:

### Session 4 | Disparities in Health Care Access, Utilization, and Quality

*Session Co-Chairs: Chanee Fabius and Emerald T. Nguyen*

It's About the Who and Where: The Role of Person and Place in Access and Quality of Care

Speaker: **Shekinah Fashaw-Walters**

Evidence of Health Information Technology and Reduced Health Disparities in Dementia Care

Speaker: **Jie Chen**

Health Care and Insurance Policies Affecting Care Use and Quality

Speaker: **Norma B. Coe**

Session 4 Research Gaps and Opportunities

Speaker: **Chanee Fabius**

Panelist Remarks

Speakers: **Emmanuel Fulgence Drabo**, **Maricruz Rivera-Hernandez**, and **Tina Sadarangani**

Moderated Discussion and Q&A

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**2:05 p.m. – 2:15 p.m. ET: Break**

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**2:15 p.m. – 3:20 p.m. ET:**

**Session 5 | Support for Care Partners and Caregivers**

*Session Co-Chairs: Kenneth W. Hepburn and Liz Necka*

Informal Dementia Care: Context Matters

Speaker: **Karen A. Roberto**

The Sooner the Better: Implementation Considerations When Initiating Intervention Development

Speaker: **Joseph E. Gaugler**

Expanding Policy Supports to Promote Caregiver Resilience and Well-Being

Speaker: **Courtney Van Houtven**

Session 5 Research Gaps and Opportunities

Speaker: **Kenneth W. Hepburn**

Panelist Remarks

Speaker: **Rita Choula**, **Jason Resendez**, and **Cassandra Thomas**

Moderated Discussion and Q&A

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**3:20 p.m. – 3:30 p.m. ET:**

**Day 2 Closing Remarks**

Speakers: **Andrea Gilmore-Bykovskyi** and **Julie Zissimopoulos**

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**3:30 p.m. ET: Day 2 Adjourn**

## DAY 3: MARCH 22, 2023

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11:00 a.m. – 11:05 a.m. ET: Welcome

Speakers: **Andrea Gilmore-Bykovskyi** and **Julie Zissimopoulos**

11:05 a.m. – 11:20 a.m. ET: Lived Experience Panel and Stakeholder Panel Highlights

Speakers: **Dave Arnold**, **Willetha Barnette**, and **Petra Niles**

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11:20 a.m. – 12:25 p.m. ET:

### Session 6 | Dementia Care Workforce

*Session Co-chairs: Joanne Spetz and Elena Fazio*

Setting the Stage: What We Know and Don't Know About the Dementia Care Workforce

Speaker: **Bianca K. Frogner**

Challenges for the Nursing Home Direct Care Workforce and the Way Forward

Speaker: **Jasmine L. Travers**

The Direct Care Workforce in Home-Based Dementia Care: Opportunities to Improve Care

Speaker: **Jennifer M. Reckrey**

Session 6 Research Gaps and Opportunities

Speaker: **Joanne Spetz**

Panelist Remarks

Speakers: **David C. Grabowski** and **Melissa Myers-Bristol**

Moderated Discussion and Q&A

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12:25 p.m. – 1:00 p.m. ET: Lunch Break

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1:00 p.m. – 2:05 p.m. ET:

### Session 7 | Economic Impacts, Implications, and Approaches

*Session Co-Chairs: Pei-Jung Lin and Priscilla Novak*

Financial Decision Making, Cognitive Decline, and Alzheimer's Disease

Speaker: **Duke Han**

Health Care Utilization Before and After a Dementia Diagnosis in Medicare Advantage and Traditional Medicare

Speaker: **Mireille Jacobson**

Costs and Cost-Effectiveness in Dementia Care

Speaker: **Peter J. Neumann**

Session 7 Research Gaps and Opportunities

Speaker: **Pei-Jung Lin**

Panelist Remarks

Speakers: **Darius Lakdawalla**, **Helen Lamont**, and **Rachel Werner**

Moderated Discussion and Q&A

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**2:05 p.m. – 2:20 p.m. ET: Break**

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**2:20 p.m. – 3:25 p.m. ET:**

**Session 8 | Approaches to Participatory Research and Diverse Recruitment and Retention in Dementia Care Research**

*Session Co-Chairs: Crystal M. Glover and Cerise Elliott*

Unique Identity Challenges for the Recruitment of AI/AN Caregivers into Dementia Care Research

Speaker: **Jordan P. Lewis**

Insights to Engaging and Recruiting Vietnamese Americans in Dementia Caregiving Research

Speaker: **Van Ta Park**

Community Relationships are Critical for the Recruitment of African American Families in Dementia Care Research

Speaker: **Fayron Epps**

Session 8 Research Gaps and Opportunities

Speaker: **Crystal M. Glover**

Panelist Remarks

Speakers: **Christina Nguyen**, **Robert Reid**, and **Martha Williams**

Moderated Discussion and Q&A

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**3:25 p.m. – 3:45 p.m. ET:**

**Summit Closing Remarks**

Speakers: **Andrea Gilmore-Bykovskyi** and **Julie Zissimopoulos**

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**3:45 p.m. ET: Summit Adjourn**



# Speaker Biographies

## Speaker Biographies

*\*2023 Summit Steering Committee Member*

**Dave Arnold** started his career in the United States Navy right out of high school, spending 4 years on an aircraft carrier amid the Vietnam War. He married his wife, Donna, and they were stationed at the naval base in Puerto Rico where they started their family. Together they have three daughters.

Mr. Arnold joined the Maryland Transportation Authority as a police officer, then later got a job with the Air National Guard as a firefighter working at Martin State Airport. He worked there for 8 years until he was injured on the job and received disability retirement. He started coaching girls' field hockey and boys' lacrosse at the community high school and opened his own business—an ice cream and coffee shop—which he ran with his wife and daughters. His final job was as a campus police officer at Loyola College in Baltimore.

Around 2018 Mr. Arnold started experiencing problems with driving, navigation skills, and general forgetfulness, and repetition. He underwent testing including an magnetic resonance imaging (MRI) and was diagnosed with mild cognitive impairment (MCI). A few years later, the diagnosis was updated to Alzheimer's disease.

Though Mr. Arnold was devastated at first—especially since he watched his Mother suffer from Alzheimer's—he wanted to remain positive and make a difference. He tells people he meets that those living with Alzheimer's can still live their life to the fullest. He currently speaks in his community to raise awareness and educate people about what it is like to live with Alzheimer's and has started a nonprofit to raise money for Alzheimer's to help people in their community stay in their homes longer.

**Willetha King Barnette**, co-author of *The Caregiver's Secrets* and co-founder of the Institute for Family Caregiving, Inc. (IFC), speaks, writes, and conducts educational activities on unpaid family caregiving. She spent more than 20 years as the primary caregiver for her mother while raising a child, working full-time, and managing her own chronic illness. Insights gained from her experiences navigating the health care and eldercare systems formed the core of IFC's hands-on approach to family caregiver education and support.

Ms. Barnette has more than 40 years of experience in educational institutions, including insurance industry trade associations, universities, and private academies. She has been an advocate for cancer and Crohn's disease patients, a trained hospice volunteer, and guardian ad litem. She has taught family caregiver support and education classes at a local community college, is a Certified Dementia Practitioner, and is an annual guest speaker for first-year medical students during their GI rotation at a nearby public research university. She has participated in the National Institute on Aging (NIA) Impact Collaboratory and Alzheimer's Association's Lived Experience Panel as a proxy for her mother. Ms. Barnette lives and works in Durham, North Carolina, where she has long been a proponent for improving health care delivery and outcomes.

**Emmanuelle Belanger**, PhD, is an Associate Professor of Health Services, Policy & Practice at the Center for Gerontology and Healthcare Research, Brown University School of Public Health. Her background includes training in both social and health sciences. She obtained her PhD from the Departments of Psychiatry and Family Medicine at McGill University. Her doctoral dissertation was a qualitative study about patient participation in palliative care decisions. She then completed a postdoctoral fellowship at the University of Montreal Public

Health Research Institute in social epidemiology of aging. Dr. Belanger's research program involves mixed-methods designs and addresses the assessment and management of patient-reported symptoms among older adults, the delivery of end-of-life care in a variety of settings, as well as decision-making processes about palliative options of care.

**\*Antonia V. Bennett**, PhD, is an Associate Professor, Department of Health Policy and Management at the University of North Carolina (UNC) Chapel Hill and the Faculty Director of the UNC Patient-Reported Outcomes Core (PRO Core). Dr. Bennett is a health services researcher and patient-reported outcomes methodologist. Her research investigates valid and reliable approaches for assessing patient-reported outcomes in longitudinal studies, in particular symptoms, physical function, and quality of life. Her current research is focused on the use of patient-reported outcome measures by PLWD, who may be participating in dementia focused research or in clinical trials for other medical conditions (e.g., cancer, heart disease). The objective is to determine at what level of cognitive impairment individuals can no longer provide valid and reliable responses on measures commonly used in clinical trials, and how patient-reported outcome measures could be improved to be more inclusive. The findings will guide the design of symptom and quality-of-life assessment in clinical trials of older adult populations. Dr. Bennett's research also tests novel methods of assessment. During the development and validation of the National Cancer Institute (NCI) Patient Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE), she led the evaluation of mode-equivalence across the tablet, IVRS, and paper forms of the PRO-CTCAE. She is also investigating the potential value of activity trackers and other wearable device data in clinical trials and clinical care.

Dr. Bennett serves on the Patient and Caregiver Relevant Outcomes Core of the NIA IMPACT Collaboratory and as Director of the Measurement Core of the National Institute of Nursing Research (NINR)-supported Palliative Care Research Cooperative.

**Leslie Burger**, MD, an internist, served in the United States Army for 33 years, where he retired as a major general; in the United States Veterans Health Administration for 7 years, where he served as Chief Medical Officer and then director of a four-state region; and as a member and past Chair of the Washington State Medical Commission for 10 years.

Over the course of his career, he held numerous positions as a practitioner and health care executive. He retired in 2016 to provide care for his wife who developed symptoms of Alzheimer's disease in 2015.

After her diagnosis and while she was able, both Dr. Burger and his wife worked tirelessly to improve funding for research and clinical care at the local, state, and federal levels, and to educate the public. After his wife passed away in 2021, Dr. Burger began volunteering at an adult day care setting and supporting various efforts to assist caregivers and those afflicted with this dreaded disease. He lives in a retirement community in northern Virginia.

**Jie Chen**, PhD, is a Professor in the Department of Health Policy and Management and Director of the Hospital And Public health interdisciplinary research (HAPPY) Lab in the School of Public Health at the University of Maryland at College Park. Her research fields include health disparities, system integration, health information technology, health policy, and dementia care. Dr. Chen is the author of more than 150 scholarly articles and has led multiple projects funded by federal agencies. Currently, Dr. Chen serves as a Principal Investigator (PI) on an R01 project funded by NIA to examine the effect of hospital and community care coordination on health care quality and equity among individuals with risk factors or diagnosis of ADRD. Her research has indicated that

innovative health care delivery models and infrastructures, such as Accountable Care Organizations and health information technology, can promote hospital and community collaboration, improve health care quality, and reduce racial and ethnic and urban and rural disparities.

Dr. Chen has 20 years of research experience working with large secondary data sets and claims data and developing, refining, and applying analytical methods. Dr. Chen has worked closely with local health departments, hospitals, and community partners to design, develop, and evaluate community interventions. Her passion is to break down longstanding silos between health care delivery systems and build age-friendly ADRD-care capable hospital-community integrated systems that deliver personalized patient-centered care to promote population health for all.

**Nathaniel Chin, MD**, is an Assistant Professor in the Division of Geriatrics and Gerontology in the Department of Medicine at the University of Wisconsin (UW). He serves as Medical Director and Clinical Core Co-Leader for the Wisconsin Alzheimer's Disease Research Center (ADRC) and Medical Director for the Wisconsin Registry for Alzheimer's Prevention (WRAP). Dr. Chin grew up in Watertown, Wisconsin, and earned undergraduate and medical degrees from UW-Madison. While completing his internal medicine residency at the University of California, San Diego (UCSD), Dr. Chin's father was diagnosed with Alzheimer's disease. His father's condition influenced the way he began to look at his own career, and Dr. Chin decided to pursue a career as a geriatrician and scientist focused on dementia, specifically Alzheimer's disease. Dr. Chin sees patients in the UW Health Memory Clinic three half-days a week.

Dr. Chin is the host of the Wisconsin ADRC's podcast, "Dementia Matters." In each bi-weekly episode, he interviews local and national Alzheimer's disease experts about research advances and caregiver strategies.

Dr. Chin's research examines modifiable risk factors and biomarker disclosure within the Wisconsin ADRC and WRAP study. He collaborates with many of the researchers at the WI ADRC and oversees the clinical care provided to the research participants.

**Rita B. Choula, MA**, is the Director of Caregiving at the AARP Public Policy Institute. In her role, she drives the strategic direction and development of family caregiving initiatives by providing content expertise, both within AARP and in partnership with a range of external stakeholders. Her work bridges policy and research to practice, centered on identifying and supporting needs of diverse family caregivers across ethnicities, cultures, and generations. Ms. Choula advances equitable, culturally-responsive policies and practices by elevating the unique nature of each caregiving experience.

In collaboration with clinical experts and key stakeholders, Ms. Choula leads the development of programs and tools that enable health care and social service professionals to better recognize the diverse needs of family caregivers and provide supports to them across settings. She currently drives AARP's efforts to address systemic disparities and build equity in long-term care for Black, Latino, Asian American Pacific Islander, and LGBTQ older adults and their family caregivers.

Most recently, Ms. Choula spearheaded a multi-million-dollar grant initiative focused on elevating the recognition and support of family caregivers providing complex care by health care professionals, particularly those in hospitals and health systems, through the intersection of policy, research, and practice.

Moved by her personal experience serving as a family caregiver for her grandmother and then mother who lived with Frontotemporal Dementia, while caring for her two small children, Ms. Choula is driven to ensure systems

are structured to meet the holistic needs of family caregivers, addressing their unique experiences and enabling them to manage their own wellbeing while providing care to others.

**Carolyn Clevenger**, DNP, RN, GNP-BC, AGPCNP-BC, FAANP, FGSA is a gerontological nurse practitioner, Professor at the Nell Hodgson Woodruff School of Nursing at Emory University, and Director of Integrated Memory Care. She is a Past President of the Gerontological Advanced Practice Nurses Association and a Fellow of the American Association of Nurse Practitioners, the Gerontological Society of America, and the American Academy of Nursing.

Dr. Clevenger's program of research includes the geriatric nurse practitioner workforce, psychoeducation programs for dementia family caregivers, and new models of care. She is co-PI for Caregiving during Crisis, Tele-Savvy@Home, and co-investigator for Savvy Caregiver Facilitator Training. She is a faculty of the Dementia Care Specialist course supported by the John A. Hartford Foundation, GAPNA, and the UCLA Alzheimer's and Dementia Care program. Dr. Clevenger is co-investigator for Georgia Gear, the state's Geriatric Workforce Enhancement Program, and the nurse practitioner representative for the Georgia Board for Healthcare Workforce.

**Norma B. Coe**, PhD, is an economist and an Associate Professor of Medical Ethics and Health Policy at the Perelman School of Medicine, a Co-Director of the Population Aging Research Center (PARC), and a Co-Director of the Get Experience in Aging Research Undergraduate Program (GEAR UP). Her research interests are in health economics and public finance. Dr. Coe's work strives to identify causal effects of policies that directly and indirectly impact health, human behavior, health care access, and health care utilization. A major focus of her research has been long-term care access, costs, insurance, and delivery, with a particular emphasis on people living with AD/ADRD.

**Linda M. Collins**, PhD, is a Professor of Global Public Health in the Department of Social and Behavioral Sciences at New York University, with a secondary appointment in the Department of Biostatistics. She is also Director of the Center for Advancement and Dissemination of Intervention Optimization (cadio). She earned her BA in psychology at the University of Connecticut and her PhD in quantitative psychology at the University of Southern California (USC).

Dr. Collins' research interests are focused on the development, dissemination, and application of the multiphase optimization strategy (MOST), a framework for the optimization of behavioral, biobehavioral, and social-structural interventions. The objective of MOST is to improve intervention effectiveness, efficiency, economy, and scalability. She is currently collaborating on research applying MOST in the areas of smoking cessation and HIV services.

Dr. Collins' research has been funded by the National Institute on Drug Abuse, the National Institute on Alcohol Abuse and Alcoholism, and the National Science Foundation, among others. She has given more than 150 presentations on MOST around the world, and her publications have appeared in journals in the fields of behavioral science, quantitative methodology, medicine, and engineering.

Dr. Collins has held tenured faculty positions at USC and at Penn State University, where she was Distinguished Professor of Human Development and Family Studies and Director of The Methodology Center. She is a Fellow of the American Psychological Association and the Society of Behavioral Medicine and is a Past President of the Society of Multivariate Experimental Psychology and the Society for Prevention Research.

**Roberta Cruz** is honored to continue to be a caregiver and care coordinator for her mother, Zenaida, who is living in the late stage of Alzheimer's disease under hospice care.

It has been a long, unpredictable, and *full* journey that began with noticeable symptoms of cognitive changes in her Mom in November 2014 in Durham, North Carolina, during a visit to spend time with her only grandson (then 1 year old). Soon after in March 2015, Zenaida moved in with Ms. Cruz's family to receive the support she needed. Since then, the caregiving experience has challenged Ms. Cruz and her young family to live fully each day while raising young children and simultaneously caring for her mother. Her caregiving adventure has crossed California and North Carolina state lines various times.

As Zenaida's health has declined, Ms. Cruz has navigated in-home care as well as residential care. She has navigated a path that both embraces and challenges traditional Filipino expectations of daughter caregivers. She feels this perspective is needed more than ever as a generation of Lolos/Lolas (grandpas/grandmas), who immigrated to the United States for a better life, are now facing Alzheimer's.

Ms. Cruz's transition back to work outside of the home has corresponded with her role as a coordinator of care for her mom in contrast to the years of providing direct daily care. These days you can find Ms. Cruz teaching UJAM dance fitness classes at the YMCA as well as working in the garden and cooking classroom at her children's elementary school. As a family, Ms. Cruz, her husband, and children find peace and joy in exploring nature in the canyons and at the shorelines of San Diego.

**Emmanuel Fulgence Drabo**, PhD, MPhil, is an Assistant Professor of Health Economics and Economic Evaluation in the Department of Health Policy and Management within the Johns Hopkins University Bloomberg School of Public Health. His research focuses on applying economic epidemiology, health services research, and systems science methods to assess the value of public health interventions. His research is primarily focused on developing and applying novel methods to estimate the impact of health interventions and public health policy changes on morbidity and mortality from infectious diseases (e.g., HIV/AIDS and vaccine-preventable diseases) and major chronic conditions (e.g., AD/DRD, cardiovascular and cardiometabolic diseases). This research effort aims to advance the science around the valuation of interventions for improving individual health outcomes and overall population health and reducing health disparities. Dr. Drabo is a Core Faculty of the Hopkins' Economics of Alzheimer's Disease & Services Center (HEADS), the Roger C. Lipitz Center for Integrated Health Care, the Center for Health Services and Outcomes Research (CHSOR), and the Hopkins Business of Health Initiative (HBHI). He is a recent USC-RCMAR Scholar, HEADS Center Year 1 Pilot awardee, and a current JHAD-RCMAR Accelerator Program awardee.

**\*Basil Eldadah**, MD, PhD, is a Supervisory Medical Officer in the NIA Division of Geriatrics and Clinical Gerontology. Dr. Eldadah oversees a portfolio of translational and clinical research in older adults across a variety of areas and mechanisms including palliative care and symptom management (e.g., pain and fatigue), HIV/AIDS, and geriatric oncology. He also helps oversee the Claude D. Pepper Older Americans Independence Centers.

Dr. Eldadah received his MD and PhD degrees from Georgetown University School of Medicine, followed by a residency in internal medicine at Georgetown University Hospital and a fellowship in Clinical Pharmacology at the NIH Clinical Center with an emphasis on autonomic physiology and neurocardiologic disorders. He has been at NIA since 2006.

**\*Cerise Elliott**, PhD, is a Program Director for the Clinical Interventions and Diagnostics Branch of the NIA Division of Neuroscience (DN). She has been a member of the DN staff since January 2008, creating evaluation and management systems for multiple research portfolios. She co-leads the Alzheimer's Disease Research Centers program and maintains an interest in health equity for Alzheimer's disease research. She previously held positions at NIH in the Office of Intramural Research and the Office of Extramural Research for the Office of the NIH Director from 2004 to 2008 where she was the liaison with nonprofit organizations, patient advocacy groups, drug industry, and individuals to disseminate NIH policies and programs effectively and creatively to stakeholders.

Dr. Elliott received her BS in chemistry from Creighton University and her PhD in neuroscience from the University of Nebraska Medical Center. Her scientific research focused on cell apoptosis controlled by peripheral T cells in multiple sclerosis. Her recent programmatic interests are creating new and effective scientific collaborations, facilitating successful mentoring relationships among grantees, and providing effective evaluation of program development.

**Fayron Epps**, PhD, RN, FGSA, FAAN, is an Assistant Professor, tenure track, who joined the Nell Hodgson Woodruff School of Nursing in August 2019. She has more than 20 years of nursing experience. Dr. Epps completed her doctoral degree in nursing from Southern University and A&M College. She has an MS in nursing (Health Care Systems Management) from Loyola University New Orleans and a BS in nursing from Tuskegee University. In 2015, she completed her postdoctoral fellowship with the National Hartford Center of Gerontological Nursing Excellence. She is a 2018-2019 Tideswell Emerging Leaders in Aging Scholar. She currently serves on the Board of Directors for Southern Gerontological Society, Alzheimer's Association Georgia Chapter, and Meals on Wheels Atlanta. She also serves on the Leadership Core of the Public Health Center of Excellence in Dementia Caregiving at the University of Minnesota.

Dr. Epps's career goal as a nurse scholar is to promote the quality of life for families affected by dementia through research, education, and service. Her program of research involves evidence-based practices for promoting quality of life for African Americans with dementia and their family caregivers. She is particularly interested in exploring ways religious activities and spiritual connectedness can promote meaningful engagement among persons with dementia. Dr. Epps oversees several faith-based and psychoeducation research projects, such as "Faith-HAT," "Dementia-Friendly Online Worship," and "Caregiving while Black." Her research has been sponsored by federal and private funding agencies. Dr. Epps is also the founder of the only nurse-led dementia friendly congregation program, Alter. For this program, Dr. Epps and her interdisciplinary team partner with African American faith communities to provide them with the necessary tools and resources needed to support families facing dementia.

**Gary P. Epstein-Lubow**, MD, is an Associate Professor of Psychiatry & Human Behavior and Associate Professor of Medical Science at the Alpert Medical School of Brown University, and Associate Professor of Health Services, Policy and Practice at the Brown University School of Public Health. Dr. Epstein-Lubow is a national leader regarding dementia services delivery; he currently leads or contributes to the leadership team of dementia-related research or workforce development projects funded by NIH, the U.S. Administration for Community Living (ACL), the U.S. Centers for Disease Control and Prevention (CDC), the U.S. Centers for Medicare & Medicaid Services (CMS), and the John A. Hartford Foundation. He is a health services investigator and geriatric psychiatrist, providing outpatient and inpatient services at Butler Hospital in Providence, Rhode Island.

In Rhode Island, Dr. Epstein-Lubow co-leads the Office of Healthy Aging's Alzheimer's Disease Programs Initiative (ADPI), supported by ACL. This project works with state leadership including the Rhode Island Department of Health to enhance the experience of care for all Rhode Islanders living with dementia and their caregivers.

He was a 2016-2017 fellow in the Health and Aging Policy Fellows Program. He also served from 2015 to 2019 as a nonfederal member of the U.S. Department of HHS Advisory Council for Alzheimer's Research, Care, and Services, where he was the nonfederal lead for the clinical care subcommittee, including work he organized regarding PLWD as stakeholders informing national research efforts for dementia care.

**\*Chanee Fabius**, PhD, MA, is an Assistant Professor of Health Policy and Management within the Johns Hopkins Bloomberg School of Public Health. Dr. Fabius 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 care management experience, where she helped older adults remain at home and delay the need for nursing home care. She is a 2021 recipient of an IMPACT Collaboratory Career Development Award to examine ways to better engage and integrate direct care workers into care delivery for persons living with ADRD. Dr. Fabius was recently awarded an NIA-funded K01, "Improving Information Sharing Between Family Caregivers and Home Care Aides Caring for Persons Living with ADRD," in which she will develop an intervention to better clarify roles between family caregivers and home care aides and identify older adult preferences for those living with ADRD and receiving Medicaid Home and Community-Based Services in Maryland. Dr. Fabius is the immediate Past-Chair of the Long-Term Services and Supports interest group for AcademyHealth and an active member of the Gerontological Society of America. Dr. Fabius 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.

**Shekinah Fashaw-Walters**, PhD, MSPH, is an Assistant Professor in the Division of Health Policy and Management at the University of Minnesota. As a health services researcher, Dr. Shekinah Fashaw-Walters' program of research focuses on understanding the inequities in aging while elucidating and explicitly naming racism as a fundamental determinant of health inequities within post-acute and long-term care. She conducts research across the long-term services and support continuum, and her work is inspired and guided by her commitment to anti-racist work that moves beyond the ivory tower. Dr. Fashaw-Walters is a health equity and aging tenure-track Assistant Professor in the Division of Health Policy & Management at the University of Minnesota's School of Public Health and is a graduate of Brown University, UNC Chapel Hill, and the University of Central Florida. Dr. Fashaw-Walters is also the 2022-2023 Fesler-Lampert Chair in Aging studies, and a faculty affiliate with the Center for Antiracism Research for Health Equity and the Center for Healthy Aging and Innovation. Dr. Fashaw-Walters envisions a society where the strength, autonomy, dignity, and independence of all older adults are enhanced by policies and practices that promote healthy and equitable aging. Her work will continue to build an anti-racist narrative that empowers effective policy solutions and health care practice innovations.

**\*Elena Fazio**, PhD, is Director of the Office of AD/ADRD Strategic Coordination (OASC) in the NIA Division of Behavioral and Social Research (BSR). OASC works to align priorities with those of the National Alzheimer's

Project Act (NAPA) and to make progress toward the plan's goals of preventing, effectively treating, and supporting care for PLWD and their care partners. While continuing to support AD/ADRD research, OASC works with academic and industry experts, as well as innovators and public advocates, to develop AD/ADRD Research Implementation Milestones through NIA-supported Research Summits that serve the purpose of detailing steps and success criteria for achieving scientific goals. OASC's and BSR's participation in developing the research implementation milestones also helps to inform the annual NIH Alzheimer's Disease Bypass Budget.

Dr. Fazio also serves as a Program Director/Program Official in BSR's Population and Social Processes Branch. Her research portfolio and scientific interests include health care systems, long-term services and supports, aging in place, health care disparities, palliative and end-of-life care, dementia care, impact of pre-symptomatic dementia diagnosis, social isolation and kinlessness, the dementia care workforce, the demography of aging, and home and community-based services. Prior to joining NIA, Dr. Fazio worked for ACL where she led a wide variety of projects focused on program performance, national data collection, and research on services and supports provided to older adults and persons living with disabilities. Before joining NIA and ACL, she was Staff Director for the Federal Interagency Forum on Aging-related Statistics. As a postdoctoral 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.

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

**Bianca Frogner**, PhD, is a Professor in the Department of Family Medicine, Director of the Center for Health Workforce Studies, and Deputy Director of the Primary Care Innovation Lab in the School of Medicine at the University of Washington (UW). She also holds an adjunct appointment in the UW Department of Health Systems and Population Health. Dr. Frogner received her PhD from the Johns Hopkins Bloomberg School of Public Health and her bachelor's degree in molecular and cell biology from University of California, Berkeley.

Dr. Frogner serves on the editorial boards of *Medical Care Research and Review* and *Health Systems*. She received the 2019 John M. Eisenberg Article of the Year Award from the *Health Services Research* journal for her collaborative work with George Washington University on the benefits of accessing physical therapists as the first point of care for low back pain. She is the PI for two Health Workforce Research Center Grants from the Health Resources and Services Administration (HRSA) to study the allied health workforce and health workforce diversity/health equity. In 2016, Dr. Frogner served on an Institute of Medicine (IOM) Consensus Study Committee on Educating Health Professionals to Address the Social Determinants of Health.

Dr. Frogner's research goal is to improve the way we spend the nation's health care dollars. She enjoys looking at patterns using big data and adapting tools from other fields to solve health care problems. She has conducted comparisons of international health systems, tested the impact of different health insurance reimbursement models, evaluated implementation of technologies such as health IT, and investigated models for better recruitment and training of our health workforce. She is also looking for ways to improve the next generation of health care technologies with a particular focus on improving the support of caregivers.

**Joseph E. Gaugler**, PhD, is a Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging at the School of Public Health within the University of Minnesota. Dr. Gaugler's research examines the sources and effectiveness of long-term care for persons with Alzheimer's disease and other chronic conditions. An applied gerontologist, Dr. Gaugler's interests include Alzheimer's disease and long-term care, the longitudinal ramifications of family care for persons with dementia and other chronic conditions, and the effectiveness of community-based and psychosocial services for older adults with dementia and their caregiving families. Underpinning these substantive areas, Dr. Gaugler also has interests in mixed methods and implementation science.

**\*Melissa Gerald**, PhD, is a Program Officer in the NIA Division of Behavioral and Social Research. Dr. Gerald's portfolio is focused on caregiving and care in clinical care and long-term care settings, priority and vulnerable populations, and behavioral and social research on aging in animals. She also directs NIA's Resource Centers for Minority Aging Research program. Dr. Gerald serves on NIA's HIV/AIDS Working Group, NIH's Violence Research Working Group, and Sexual & Gender Minority Research Coordinating Committees, and she represents NIH on the Elder Justice Interagency Working Group and as a federal member of the Family Caregiving Advisory Council overseen by the Secretary of the Department of Health and Human Services. Before joining NIA, Dr. Gerald served as Scientific Review Officer at NIH's Center for Scientific Review; Associate Professor at the University of Puerto Rico, Medical Sciences Campus in the Department of Internal Medicine; and Scientist-in-Charge of the Cayo Santiago Field Station of free-ranging rhesus macaques. She received postdoctoral training in the Laboratory of Clinical and Translational Studies' Primate Section within the intramural research program at the National Institute on Alcohol Abuse and Alcoholism. Dr. Gerald earned her bachelor's degree in anthropology and psychology at the University of Wisconsin-Madison and her MA and PhD in anthropology at UCLA.

**Heidi Gil** is LiveWell's Chief Strategy Officer, bringing more than 30 years of experience in transforming the health care experience, while successfully improving financial, clinical, and operational performance. Ms. Gil achieved these results as a known innovator in driving evidence-based, person-centered innovations through the engagement of multi-stakeholders from local to international levels. This work began with leading the development of "Planetree Continuing Care," adapting the internationally renowned patient-centered acute care model to the needs of post-acute environments and healthy communities. Ms. Gil worked to expand their network and provided strategic planning and coaching services to more than 250 CEOs and their respective leadership teams and staff. Through multiple grants, Ms. Gil has led start-up innovations aimed at repositioning and diversifying services and supports. She has empowered individuals with lived experience and stakeholders to reimagine health and well-being through transforming how programs and environments are designed and experienced. Ms. Gil led the Eugene Washington Patients-Centered Outcomes Research Institute (PCORI) Award: "Empowering Partnership: Preparing People with Dementia to Partner with Researchers." As a novel project in the United States, a multi-stakeholder group composed of PLWD, care partners, researchers, and stakeholders

came together to work toward the common goal of enhancing the participation of PLWD in all aspects of research. This project underscores her dedication to empowering the voices of those impacted to lead and emerge breakthrough change on an individual and systems level. She is also a member of the NIA IMPACT Collaboratory's Stakeholder Engagement Team.

**\*Andrea Gilmore-Bykovskyi**, PhD, RN, is an Associate Professor and Associate Vice Chair of Research in the BerbeeWalsh Department of Emergency Medicine at the University of Wisconsin School of Medicine and Public Health. She also serves as Deputy Director of the University of Wisconsin-Madison Center for Health Disparities Research (CHDR) and Informatics Lead for the University of Wisconsin Alzheimer's Disease Research Center (ADRC) Care Research Core.

Dr. Gilmore-Bykovskyi leads a funded program of research focused on promoting effective, meaningful, and equitable care and research for PLWD. Her research addresses structural and health systems barriers to optimal care for PLWD and their caregivers, particularly during challenging points in the health and care continuum such as during acute illness, transitions in care, and advanced disease. Dr. Gilmore-Bykovskyi has led advances in geriatric health services research that have stewarded new areas of investigation surrounding dementia-specific care delivery patterns and outcomes, and developed frameworks to advance practices of scientific inclusion. Her current work focuses on identifying and characterizing episodes of lucidity in people living with advanced dementia.

Across her research activities, Dr. Gilmore-Bykovskyi is committed to engaging with community and clinician partners and working directly with PLWD and their caregivers to fully integrate their perspectives into the research process and results.

**\*Crystal M. Glover**, PhD, is an applied social psychologist, mixed-methodologist, and health equity in aging researcher at the Rush Alzheimer's Disease Center and an Associate Professor of Psychiatry and Behavioral Sciences (and) Neurological Sciences in Rush Medical College. She also leads the Outreach, Recruitment, and Engagement Core at the Rush Alzheimer's Disease Center.

Dr. Glover received her doctorate in social psychology and neuropsychology from Howard University and completed her postdoctoral research fellowship at Dartmouth Geisel School of Medicine. She was competitively awarded a BMO Harris Bank Health Disparities Research Fellowship within the Department of Preventive Medicine at Rush Medical College. Dr. Glover joined the faculty of the Rush Alzheimer's Disease Center in 2016.

Dr. Glover's areas of interest include health equity and health disparities, structural and psychosocial determinants of health, intersectionality as a conceptual framework and methodology, and social cognitive processes. She focuses her research and related efforts on understanding and facilitating healthy aging across all demographic groups but with a special concentration on collaborating with and inclusion of communities that have been inequitably included and traditionally understudied in aging research. One of her NIH-funded research projects focuses on decision making regarding brain donation among older adults representing racial, ethnic, and economic minoritized groups.

Dr. Glover has widely published her peer-reviewed work in several high-impact scientific journals, including *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, *CHEST*, and *Human Genetics*. She continues to present her research at international and national scientific meetings, and belongs to several professional

groups, including The Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART) and the CDC BOLD Public Health Center of Excellence on Dementia Risk Reduction. Overall, Dr. Glover dedicates her work to eradicating health disparities and creating health equity—globally, nationally, and locally.

**David C. Grabowski**, PhD, is a Professor of Health Care Policy in the Department of Health Care Policy at Harvard Medical School. His research examines the economics of aging with a particular interest in the areas of long-term care and post-acute care. He has published more than 200 peer-reviewed articles, and his work has appeared in leading peer-reviewed journals of economics, health policy, and medicine, including the *Review of Economics & Statistics*, *Health Affairs*, the *Journal of Health Economics*, and the *New England Journal of Medicine*. His work has been featured by prominent popular press outlets, such as the *Wall Street Journal*, National Public Radio, *Washington Post*, and *New York Times*. He has testified to Congress on four separate occasions.

Dr. Grabowski's research has been supported by NIA, AHRQ, and CMS. His research has also been funded by several private foundations including the Robert Wood Johnson Foundation, Commonwealth Fund, Arnold Foundation, Donaghue Foundation, and Warren Alpert Foundation.

Dr. Grabowski is a member of the Medicare Payment Advisory Commission (MedPAC), which is an independent agency established to advise the U.S. Congress on issues affecting the Medicare program. He is an Associate Editor of the journal *Forum for Health Economics and Policy*, and he is a member of the editorial boards of *American Journal of Health Economics*, *B.E. Journals in Economic Analysis & Policy*, and *Journal of the American Medical Directors Association*. He was the 2004 recipient of the Thompson Prize for Young Investigators from the Association of University Programs in Health Administration.

Dr. Grabowski received his BA from Duke University and his PhD in public policy from the Irving B. Harris School of Public Policy at the University of Chicago.

**Duke Han**, PhD, is a Diplomate of the American Board of Professional Psychology in Clinical Neuropsychology, a Fellow of the American Psychological Association and the National Academy of Neuropsychology, Director of the Neuropsychology Division in Family Medicine, and a tenured Professor of Family Medicine, Neurology, Psychology, and Gerontology at the USC Keck School of Medicine.

Dr. Han received his BS in psychology with a specialization in neuroscience from Duke University, and his PhD in clinical psychology from the University of Massachusetts Boston. He received training in clinical neuropsychology and experimental neuroimaging techniques through various programs of Harvard Medical School's Brigham and Women's Hospital. He continued his clinical neuropsychology and neuroimaging activities during his internship and postdoctoral fellowship years at UCSD and the San Diego VA Healthcare System. He maintains an active research collaboration with the Rush Alzheimer's Disease Center in Chicago where he was formerly a tenured faculty member.

Dr. Han is interested in the factors that affect cognition and decision making in aging. He also has special interests in leveraging novel empirical approaches to better understand these factors, and in the advocacy of justice, equity, diversity, and inclusion considerations in aging and neuroscience research. He was the recipient of the prestigious Paul B. Beeson fellowship, which is considered the premiere career development award of NIA. He is the primary investigator or co-investigator on multiple research grants extramurally funded by NIH and private foundations. He is actively involved in the peer-review of aging and Alzheimer's Disease research

grants and has previously served as the Chair of the NIA Clinical and Translational Research of Aging review committee and the Neuroscience of Aging review committee.

**Reda Harrison** grew up in Southern California, moving to her parents' home state of Kentucky after high school. Ms. Harrison began working at the University of Kentucky in its medical records department at age 17, working in various departments at the University for nearly 30 years, most recently as a surgery coordinator for its plastic surgery department.

In 2018 Ms. Harrison noticed memory problems for the first time while returning from work after a weeklong vacation. She called her university's memory clinic and following a series of cognitive tests, received a diagnosis of dementia and was told to come back for a follow-up appointment in 6 months. The abrupt manner in which her diagnosis and follow-up was handled left her shocked. Frustrated and confused, Ms. Harrison began gathering as much information as she could on dementia. She connected with the Alzheimer's Association and became active with a local early-stage support group. A turning point in her disease education came when she was invited to join a group study for people with MCI at the University of Kentucky Sanders-Brown Center on Aging.

Following a 6-week work furlough during the COVID pandemic, she realized she felt better without the stress of work. After applying for social security disability income, refinancing her home, and paying down outstanding debt, she retired in 2021. Today, Ms. Harrison dedicates herself to pursuing health lifestyle interventions that she hopes will slow her cognitive decline, including daily walks with her Standard Poodle named Dolly, which she is training to be her service dog. By sharing her experience, Ms. Harrison wants to encourage others to be proactive in taking charge of their well-being in the wake of an Alzheimer's or dementia diagnosis.

Ms. Harrison and her husband Joe live in Nicholasville, Kentucky. They have four children.

**Kathi L. Heffner**, PhD, is a Professor of Nursing, Medicine, and Psychiatry, and the Associate Chief of Research in the Division of Geriatrics and Aging in the Department of Medicine at the University of Rochester (UR) Medical Center. Her multidisciplinary and interprofessional collaborations and mentorship are aimed at supporting research initiatives that can ultimately foster individuals' health and well-being in later life.

Dr. Heffner's work has been supported by multiple organizational, NIH, and other federally funded grants. Her growing leadership in aging research has been recognized locally and nationally, including as a selected scholar for the Tideswell UCSF Emerging Leaders in Aging Program. She is currently the PI and Program Director for the Healthy Aging Research Program, supported by the UR Clinical Translational Science Institute, School of Nursing, and Department of Psychiatry.

Dr. Heffner's research centers on understanding the links between stress and health in older adulthood. She is particularly interested in how stress affects the immune system, and how to promote stress resilience to keep the immune system healthy at older ages. Her scientific contributions fall into three areas: (1) implications of stress, including older family caregivers' stress, for healthy immune aging, (2) the influence of sleep and insomnia on stress physiology and inflammation, and (3) the role of social relationships in older adults' stress and stress resilience. Across these areas, her goal is to identify behavioral interventions that can affect multiple domains of older adults' well-being, including mood and anxiety, cognitive function, pain, and risk for chronic aging-related diseases.

**\*Kenneth W. Hepburn**, PhD, is a tenured Professor in the Nell Hodgson Woodruff School of Nursing at Emory University. His work recognizes the central role that families, friends, and communities play in caring for the increasing—and increasingly diverse—number of persons living with Alzheimer's disease and similar dementia illnesses and helping them to remain as independent as possible in their communities. He sees family caregivers as occupying what is, in effect, a clinical role—or, really, an amalgam of a variety of clinical roles. As such, caregivers need training and education to help them understand the conditions with which they are dealing, to strengthen their own sense of competence to enable them to approach the role with confidence, and to develop strategies for caregiving that take the strengths and deficits of the care recipient into account. He and colleagues from a very wide range of disciplines have developed and tested programs designed to strengthen the capacity of informal caregivers to function effectively in their caregiving role in a manner that preserves their own health and well-being. They have drawn from the work of Albert Bandura in designing psychoeducation programs that strengthen caregivers' sense of self-efficacy for caregiving. Through a series of projects that, with support from NIA, the National Institute of Nursing Research, and the national Alzheimer's Association, Dr. Hepburn and his colleagues have established the evidence base for the Savvy Caregiver Program and Tele-Savvy (an online version of Savvy), psychoeducation programs for caregivers of persons with Alzheimer's disease and other dementia disorders. Dr. Hepburn is the co-Director of the Emory Roybal Center for Dementia Caregiver Mastery, an NIA-sponsored program to provide support for projects that pilot interventions designed to promote caregiving competence and confidence (mastery) in a variety of dementia caregiving contexts and situations. He is also Director of Research in the Woodruff Health Science Center for Health in Aging.

**Ula Hwang**, MD, MPH, is a Professor of Emergency Medicine at the Yale School of Medicine. She is an emergency physician and researcher interested in the quality of emergency care that older adults receive. She wrote the article first describing "The Geriatric Emergency Department," co-led the development of the 2014 Geriatric ED Guidelines that are endorsed by national Emergency Medicine and Geriatrics organizations, and she was an inaugural member of the Board of Governors for the American College of Emergency Physician's Geriatric Emergency Department Accreditation program. She is the co-PI of the Geriatric ED Collaborative (GEDC), a national implementation program supported by the John A. Hartford Foundation and the West Health Institute to educate, implement, and evaluate geriatric emergency care and is the PI and MPI of the NIA-funded Geriatric Emergency care Applied Research (GEAR) and GEAR 2.0 – Advancing Dementia Care Networks.

**Mireille Jacobson**, PhD, is an Associate Professor of Gerontology and Assistant Dean of Faculty and Academic Affairs in the School of Gerontology at USC. She is an applied micro-economist with a diverse portfolio of research united by an interest in understanding how health care policies affect well-being. Much of her work focuses on the supply-side of health care markets, analyzing the effects of direct supply changes (e.g., hospital closures) on access to care and of reimbursement policy on treatment and outcomes, specifically in the oncology market. Other work focuses on the demand side, assessing the impact of financial incentives on vaccination decisions. Her current research projects include a large study testing both remote and in-person approaches to increase the diversity of participants in a brain health registry, a study testing approaches to increase COVID-19 booster vaccination rates, and a comparison of differences in health care use for persons with dementia in traditional Medicare versus Medicare Advantage. Professor Jacobson is an Associate Professor in the Davis School of Gerontology, Co-Director of the program on aging at the USC Schaeffer Center for Health Policy & Economics, and a Research Associate in the Health Care Program at the National Bureau of Economic Research. She is also a member of the National Advisory Council for AHRQ.

**Lee A. Jennings, MD, MSHS, AGSF**, is Chief and Associate Professor of Medicine at Reynolds Section of Geriatrics and Palliative Medicine at the University of Oklahoma Health Sciences Center. Dr. Jennings is a geriatrician and health services researcher whose work focuses on improving models of care delivery for dementia and aligning care received with patient health goals. She has established a statewide older adult health education and community outreach program focused on dementia health care workforce development and fall prevention in Oklahoma. She is the Director of the HRSA-funded Oklahoma Geriatric Workforce Enhancement Program, PI for the ACL-funded Oklahoma Falls Prevention Program, and a multi-PI for an AHRQ-funded grant to reduce opiate use disorder and improve chronic pain management in Oklahoma primary care practices. She is a co-investigator on ADRD research funded by the Patient-Centered Outcomes Research Institute, NIA, and The John A. Hartford Foundation. She is a graduate of the Tideswell Emerging Leaders in Aging program, sits on the editorial board for the *Journal of the American Geriatrics Society*, and co-chairs the Women in Geriatrics Section for the American Geriatrics Society.

**Deborah (“Deb”) Jobe** is happily married for over 16 years to her husband Jon. She has two children, one grandchild, and two four-legged “kids.” Ms. Jobe was diagnosed with posterior cortical atrophy (PCA) associated with Cortical Basal Syndrome and MCI in 2019 at age 53. At that time, she worked in the Human Capital Management Managed Global space for over 30 years with Fortune 500 companies overseeing the customer experience.

Post diagnosis, Ms. Jobe turned her energies toward advocacy with the Alzheimer’s Association and other organizations focusing on public policy, research, early detection, and intervention strategies, education, and public awareness. She has met with legislators on national and state levels; featured in numerous videos and print publications; and serves as a Patient Advocate for The Geriatric Emergency Care Applied Research Network (G.E.A.R. 2.0) to advance the science of improving emergency care for PLWD. She is also an alumnus of the 2021-2022 Alzheimer’s Association National Early-Stage Advisory Group.

Ms. Jobe continues to focus her efforts on living well with dementia, dispelling stigma, and advancing quality of care for persons living with dementia and their care partners.

**Amy Kelley, MD, MSHS**, is the Deputy Director of NIA. Dr. Kelley works closely with the NIA Director, provides strategic leadership, supervises daily operations, and serves as an ambassador and spokesperson for the Institute. As NIA’s chief diversity officer, she oversees diversity, equity, inclusion, and accessibility initiatives.

Prior to joining NIH, Dr. Kelley was Professor and Vice Chair for Health Policy and Faculty Development, Hermann Merkin Professor in Palliative Care in the Brookdale Department of Geriatrics and Palliative Medicine, and Senior Associate Dean for Gender Equity in Research Affairs at the Icahn School of Medicine at Mount Sinai in New York. Her meritorious research—which bridged geriatrics and palliative medicine by focusing on the needs of seriously ill older adults and their families—was supported by NIA through multiple grants, including a Paul B. Beeson Emerging Leaders Career Development Award in Aging.

Dr. Kelley has extensive experience using the nationally representative, longitudinal Health and Retirement Study (HRS) and National Health and Aging Trends Study (NHATS), both linked with Medicare claims data, to examine factors associated with treatment intensity among older people living with ADRD, and other serious illnesses. Her work has examined the financial burdens faced by patients and families living with serious illness and demonstrated that only 11 percent of the highest-cost patients are in the last year of life, supporting the need to prospectively identify those older adults who are at greatest risk for high health care costs and may have unmet

care needs. She also has been closely involved with the NIA IMPACT Collaboratory.

She has been recognized broadly for her exemplary work, including by the American Geriatrics Society with the 2022 Thomas and Catherine Yoshikawa Award for Outstanding Scientific Achievement in Clinical Investigation. She is also a two-time Icahn School of Medicine at Mount Sinai “Palliative Care Clinician of the Year” honoree.

**Ian Kremer**, JD, Executive Director of the LEAD Coalition (<http://www.leadcoalition.org>), has worked on dementia policy since 1996. The LEAD Coalition, the uniting voice of more than 200 member and allied organizations, works to improve quality of life for people facing dementia while advancing the science to end dementia. The LEAD Coalition has helped to secure historic NIH funding increases, expand Medicare services for people with dementia and protect dementia-relevant components of Medicaid and the Affordable Care Act, expand roles of people with dementia and care partners in medical product development, build a nation-wide network of dementia-friendly communities, and has worked with Congress and a dozen federal agencies to advance health equity, clarify regulatory pathways, combat elder abuse, and improve cognitive impairment detection and diagnosis, clinical care, and access to home and community-based services.

Mr. Kremer served on the steering committees for NIH’s 2017 and 2020 National Research Summits. He serves on CMS’ Medicare Evidence Development & Coverage Advisory Committee, CDC’s Healthy Brain Initiative’s Leadership Committee, the Food and Drug Administration (FDA)’s Prescription Drug User Fee Act Stakeholders Working Group, and the *Public Policy & Aging Report* editorial board. Mr. Kremer also serves on steering and advisory committees for the NIA IMPACT Collaboratory, the NYU School of Medicine BOLD Public Health Center of Excellence (PHCOE) on Early Detection of Dementia, the University of Minnesota PHCOE on Dementia Caregiving, the National Healthy Brain Initiative Tribal Project, the Hopkins Economics of Alzheimer’s Disease and Services Center, the WeCareAdvisor Study, the UCLA Dementia Care Study, the Alzheimer’s Disease Patient and Caregiver Engagement initiative, and the Dementia Friendly America initiative. He was an external reviewer for NASEM’s report *Meeting the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers: A Way Forward*. Mr. Kremer holds degrees from Washington University in Saint Louis and the University of Michigan School of Law.

**Darius Lakdawalla**, PhD, holds the Quintiles Chair in Pharmaceutical Development and Regulatory Innovation at USC, where he sits on the faculties of the Mann School of Pharmacy, the Sol Price School of Public Policy, and the Leonard D. Schaeffer Center for Health Policy and Economics, one of the nation’s premier health policy research centers. He is the Director of Research at the Schaeffer Center. Dr. Lakdawalla is a widely published, award-winning researcher and a leading authority in both health economics and health policy.

His research has focused primarily on the economics of risks to health, the value and determinants of medical innovation, the economics of health insurance markets, and the industrial organization of health care markets. His work has been published in leading journals of economics, medicine, and health policy.

Dr. Lakdawalla is currently a Research Associate at the National Bureau of Economic Research and Associate Editor for the *Journal of Health Economics*. He previously served as Associate Editor at the *American Journal of Health Economics* and the *Review of Economics and Statistics*.

Dr. Lakdawalla received his PhD in economics from the University of Chicago and his bachelor’s degree in mathematics and philosophy from Amherst College.

**\*Helen Lamont**, PhD, is the Director of the Division of Disability and Aging Policy within the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the U.S. Department of Health and Human Services, where she manages a team of professional staff that conduct policy analysis, research, and evaluation related to disability, aging, and long-term care issues and programs. Dr. Lamont also leads the implementation of the National Alzheimer's Project Act, coordinating both the Advisory Council on Alzheimer's Research, Care, and Services as well as an interagency group that writes the annual National Plan to Address Alzheimer's Disease. She also leads a portfolio of research in dementia, including a project to examine the use of inpatient psychiatric facilities by people with dementia. She works on family and informal caregiving, as well as elder justice and adult maltreatment. Dr. Lamont has worked across the Department on disability data issues and has a current project to explore the feasibility of using an internet panel study to collect data on disability. She joined ASPE in 2007 and has a PhD in aging studies from the University of South Florida and a BS in human development from Duke University.

**Emily Largent**, PhD, JD, RN, is the Emanuel and Robert Hart Assistant Professor of Medical Ethics & Health Policy at the Perelman School of Medicine, and she holds a secondary appointment at the University of Pennsylvania Law School. Her research examines ethical and regulatory issues arising in human subjects research, with a particular focus on Alzheimer's disease research. Dr. Largent received her PhD in health policy (ethics) from Harvard University and her JD from Harvard Law School. Prior to that, she received her BS in nursing from the University of Pennsylvania School of Nursing and completed a fellowship in the Department of Bioethics at the National Institutes of Health.

**Eric B. Larson**, MD, MPH, is a Clinical Professor of Health Services at the UW School of Public Health and the Health Services Associate Director of the Administrative Core at ADRC. A general internist, Dr. Larson has pursued an array of research, ranging from clinical interests such as Alzheimer's disease and genomics to health services research involving technology assessment, cost-effectiveness analysis, and quality improvement. His research on aging includes a longstanding collaboration between Kaiser Permanente Washington (formerly Group Health Research Institute) and the University of Washington called the Adult Changes in Thought (ACT) study. Since 1986, the longitudinal ACT Study has followed more than 5,000 aging participants from the community from age 65 and older, collecting information on health and cognitive function every 2 years. Some develop dementia, and some agree to donate their brains at the end of life. The ACT uses this extensive data resource to identify the environmental and genetic factors that increase the risk of brain disease and find ways to help communities delay or avoid dementia.

Several of Dr. Larson's research projects are related to promoting successful aging and high functioning in seniors. With colleagues at the UW, he is executive co-producer of the Art of Aging, a news-magazine series on public television and the Web. He is also author of the book *Enlightened Aging: Building resilience for a long active life*.

Dr. Larson served as Medical Director for the UW Medical Center and Associate Dean for Clinical Affairs at its medical school from 1989 to 2002. He is a member and past President of the Society of General Internal Medicine (SGIM), having received its highest honor, the Robert J. Glaser Award, in 2004. Dr. Larson is also a Master of the American College of Physicians (ACP) and served on its Board of Regents for nearly a decade, including one term as Chair.

**Jordan P. Lewis**, PhD, MSW, is a Professor at the WWAMI School of Medical Education at the University of Alaska, Anchorage, and the Associate Director of the Memory Keepers Medical Discovery Team. Over the past decade, Dr. Lewis's research agenda has significantly contributed to the field with discussions on culture-specific approaches to successful aging. His work has established a culturally congruent Alaska Native (AN) perspective and understanding of AN successful aging and led to a theory of AN healthy aging. This research challenges the most common definitions of successful aging, which focus on the lack of disease and disability and healthy mental well-being, and instead reconstructs AN aging using a strengths-based, non-medical, systems approach perspective.

Through community-based participatory research, his work to define AN successful aging gives voice to Elders, enabling them to define their own aging processes, while contributing to concepts of Indigenous health and aging. His work with AN Elders identified a key characteristic of successful aging to be a willingness and desire to pass down their wisdom and experiences to ensure a healthy future for younger community members. His research has identified indigenous cultural generativity as a critical source of meaning and identity.

Over the past 3 years, Dr. Lewis's research agenda has expanded to include ADRD among AN Elders. He has explored the cultural understandings and constructions of ADRD, identified barriers to timely care, and assisted communities in developing culturally appropriate programming both from the perspectives of the Elders and their family caregivers. Through community-based work with tribal communities, he has identified barriers to proper assessment and diagnoses of ADRD. These include limited knowledge and lack of training of health care providers, including their understandings of ADRD from a cultural lens. As a community psychologist, Dr. Lewis is trained to work with communities to develop culturally relevant programs and services to improve the health and well-being of community members across the lifespan.

**\*Pei-Jung Lin**, PhD, is an Associate Professor of Medicine at Tufts University School of Medicine and a Project Director at the Center for the Evaluation of Value and Risk at the Institute for Clinical Research and Health Policy Studies at Tufts Medical Center. Her research interests center on health care policy, health economics and outcomes research, and cost-effectiveness analysis. The core of her work involves analyzing the value of health care and assessing quality of care, patient outcomes, and health care costs among vulnerable populations with chronic conditions. Her work addresses clinical and translational research by examining how Alzheimer's disease is being diagnosed and managed in real-world care settings. Her recent, NIH-funded R01 grant investigates racial and ethnic disparities in dementia care. Dr. Lin was awarded the Alzheimer's Association New Investigator Research Grant to examine comorbidity management and hospital outcomes among Medicare patients with Alzheimer's disease. She has served as an Associate Editor for *Alzheimer's & Dementia* since 2015. She is a Programs Chair of the Health Policy Personal Interest Area of the Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART). Dr. Lin received her MS in health policy and management from the Harvard T.H. Chan School of Public Health and her doctorate in health policy and management from the University of North Carolina at Chapel Hill.

**Shari M. Ling**, MD, serves as the CMS Deputy Chief Medical Officer. Dr. Ling's longstanding focus is on the achievement of meaningful health outcomes through the delivery of value-based care that is person centered, high quality, safe, and equitable across all care settings.

Dr. Ling has served as a CMS representative on the National Alzheimer's Plan FACA committee since its inception. She also currently serves as a CMS representative on the Behavioral Health Coordinating Council's HHS cross-department workgroups. Dr. Ling received her medical training at Georgetown University School of

Medicine, her clinical training in internal medicine and rheumatology at Georgetown University Medical Center, and her geriatric medicine training at Johns Hopkins University. She maintains a special interest in the care of PLWD and those with multiple chronic conditions and functional limitations that was sparked during her years with the NIA Intramural Research Program.

**James Mangi**, an environmental scientist and owner of a nationwide, award-winning business, was totally unprepared for his “retirement” role, which he entered suddenly when his wife developed Alzheimer’s in her later fifties.

Now, 15 years later, Mr. Mangi is the caregiver for his best friend—who has long since forgotten his name, but has not forgotten how to smile. She has inspired him to become a dementia awareness activist. As a volunteer community educator for 5 years, he has long since lost count of the classes he has given across the whole Association curriculum, but he still loves those lightbulb moments: When something in the programs he teaches lights up a person’s face with understanding. He believes Information and connection can make such a difference.

In collaboration with Association personnel, Mr. Mangi set up Dementia Friendly Saline, which led the effort to establish his small Michigan town as an officially recognized Dementia Friendly City, one of only two in Michigan. In addition to an active program of dementia friendly presentations to businesses in the area, he now manages a twice monthly program of social events for persons with dementia and their care partners. As of March, Mr. Mangi and his Dementia Friendly Team have launched the nation’s first regular monthly program of Dementia Friendly movie screening events at a local commercial movie theater.

Mr. Mangi is also the author of two books—written as “respite in situ” and published by Pen & Sword. But he does not yet understand why his daughter says he is flunking retirement.

**Brent Mausbach**, PhD, is a Professor in Residence in the Department of Psychiatry at UCSD. Dr. Mausbach obtained his PhD in clinical psychology from the Pacific Graduate School of Psychology in Palo Alto, California. He completed his clinical psychology internship at the VA Black Hills Healthcare System, after which he received post-doctoral training at both Stanford University and UCSD with a specialization in geropsychiatry. He has been a member of the faculty of the Department of Psychiatry at UCSD since July 2007. Dr. Mausbach’s research interests lie in both health psychology and psychopathology. In the area of health psychology, he has investigated the links between stress, mood disturbance, and disease risk, as well as psychological resiliency factors that may have protective effects on health outcomes. His research in this area has recently extended to examining the psychological and health benefits of behavioral psychotherapies, with an emphasis on biomarkers of disease risk. In the realm of psychopathology, he has examined predictors of functional capacity and functional outcomes in schizophrenia. This research has focused primarily on the development and refinement of performance-based measures of functional capacity, including the use of mobile technology applications for assessing functioning in schizophrenia. Dr. Mausbach has also examined the use of mobile technology as a means of enhancing skills-training interventions for middle-aged and older adults with schizophrenia.

Dr. Mausbach’s research focuses on bridging basic scientific research with clinical services. He has examined the links between stress/coping and health outcomes, with an emphasis on positive psychological states (e.g., mastery, self-efficacy) and their association with health outcomes and well-being. This research has led Dr. Mausbach to test psychosocial interventions designed to improve emotional and physical well-being in chronically stressed populations (e.g., Alzheimer’s caregivers).

**Christina S. McCrae**, PhD, DBSM, FSBM, FAASM, is a Professor and Assistant Dean of Research in the College of Nursing at the University of South Florida. For more than 20 years, Dr. McCrae has steadily built a robust portfolio of scientific, administrative, and leadership accomplishments since earning her PhD in clinical psychology from Washington University in St. Louis. As a scientist and principal investigator, Dr. McCrae has assembled an internationally and nationally recognized program of sleep research and received funding from NIH and the U.S. Department of Defense. She served as a founder and President of a new professional society, the Society of Behavioral Sleep Medicine (SBSM) where she developed the society's position paper policy, published its first position paper, and earned a Distinguished Service Award. Other national leadership experiences include chairing or serving on numerous committees and the executive board for the American Board of Sleep Medicine and the American Academy of Sleep Medicine and participating in review panels for the National Institutes of Health.

Dr. McCrae's research focuses on the biopsychosocial and neurocognitive mechanisms underlying chronic insomnia and co-occurring medical disorders across the lifespan (e.g., autism, chronic pain, dementia, heart disease, obesity).

**Ellen McCreedy**, PhD, MPH, is an Assistant Professor of Health Services, Policy, and Practice at the Center for Gerontology at the Brown University School of Public Health. Her research focuses on pragmatic evaluation of nonpharmaceutical interventions for managing neuropsychiatric symptoms in PLWD. Dr. McCreedy is currently leading an embedded pragmatic trial testing the effects of personalized music on agitation and antipsychotic use for nursing home residents with dementia, and a trial testing the effects of an enhanced advance care planning intervention on documentation of care wishes for people with dementia in assisted living centers. She has previously served as measurement lead for a trial testing the effect of tunable LED lighting on agitation and sleep for nursing home residents with dementia. Dr. McCreedy is also a Steering Committee member of the Technical and Data Core of the NIA IMbedded Pragmatic Alzheimer's disease (AD) and AD-Related Dementias (AD/ADRD) Clinical Trials (IMPACT) Collaboratory. Dr. McCreedy received her MPH in global health from the University of South Florida, her PhD in health services research from the University of Minnesota, and completed a postdoctoral research fellowship at the Brown University Center for Gerontology and Healthcare Research.

**\*Luis D. Medina**, PhD, is an Assistant Professor of Clinical Psychology and Director of the Collaborative on Aging Research and Multicultural Assessment at the University of Houston. Dr. Medina is a licensed clinical psychologist and cultural neuropsychologist. He received his BA in psychology from Yale University and his PhD in clinical psychology/neuropsychology from the San Diego State University/UCSD Joint Doctoral Program in Clinical Psychology. Dr. Medina completed his clinical internship at the West Los Angeles Veterans Affairs Medical Center (geropsychology track) followed by a postdoctoral fellowship in adult clinical neuropsychology at the University of Colorado School of Medicine. His research examines the cultural neuroscience of cognitive aging, particularly in the context of AD/ADRD, as well as the clinical assessment and diagnosis of AD/ADRD in underrepresented populations. Dr. Medina is also PI of the NIA-funded Engaging Communities of Hispanics/Latinos for Aging Research (ECHAR) Network—a community engaged research network dedicated to inclusion science.

**Sheila L. Molony**, PhD, APRN, GNP-BC, FGSA, FAAN, is a Professor of Nursing at Quinnipiac University and a Fellow of the Gerontological Society of America and the American Academy of Nursing. Dr. Molony's research emphasizes the importance of individually tailored care, actively listening to the voices of older adults and families, and using these perspectives to shape healing environments in long-term care. Dr. Molony's work

clarifies the concept of at-homeness, and she has developed a reliable and valid measure of this construct that has been used nationally and internationally. Dr. Molony studied longitudinal trajectories of at-homeness in frail nursing home residents as they experienced health and residential transitions, including older African Americans in a PACE program. Dr. Molony's work includes the publication of Dementia Care Practice Guidelines for Assessment and Care Planning in a special issue of *The Gerontologist*. Dr. Molony is currently leading an NIH/NIA-funded project using human centered design to create positive psychosocial measures for individuals living with dementia.

Dr. Molony received her BSN from Boston University, her MSN and PhD from the University of Connecticut, and her Postdoctoral Fellowship from PENN School of Nursing, in partnership with Yale University.

**Monica Moreno** is the Senior Director of Care and Support at the Alzheimer's Association®, where she provides strategic oversight in three areas: 1) Development, evaluation, and implementation of Consumer Education and Support Services; 2) Stakeholder Engagement of people living with dementia and care partners/caregivers/proxy caregivers; 3) Quality Care Initiative and Product Line to improve care delivery in long-term care and community-based settings.

Prior to becoming Senior Director of Care and Support, Ms. Moreno served as the Director of Early-Stage Initiatives, E-Services & Mission Partnerships at the Alzheimer's Association®. As Director of Early-Stage Initiatives, she was responsible for the development and implementation of the organization's national programs and strategies designed to meet the unique needs of people living in the early-stage of Alzheimer's disease or other dementias. She provided management and strategic oversight to the organization's online support services including AlzConnected (an online social networking site), Alzheimer's Navigator (an on-line care consultation), and Community Resource Finder (an online resource database).

Ms. Moreno received her bachelor's degree in social work from Loyola University, Chicago.

**Melissa Myers-Bristol**, MPA, serves as Assistant Director at Clayton County Senior Services Department. She has more than 19 years of experience in planning, developing, managing, and coordinating programs and services to support older adults, caregivers, and persons with disabilities. Prior to joining Clayton County Senior Services, she served as the Executive Director of the Alzheimer's Services Center. She received her Master of Public Administration degree from the University of Phoenix.

**\*Elizabeth Necka**, PhD, is a Program Director in the Individual and Behavioral Processes Branch of the NIA Division of Behavioral and Social Research. At NIA, Dr. Necka directs a portfolio of basic and translational research focused on interpersonal relationships in aging and how they relate to health and well-being, with particular emphasis on dyadic interactions and informal caregiving for people living with ADRD. Her portfolio also includes research on aging-related processes such as social disconnection, social cognition, and pain. Prior to joining NIA, Dr. Necka was an AAAS Science and Technology Policy Fellow and served as a Program Officer in the Division of Translational Research at the National Institute of Mental Health, where she managed a portfolio of grants on the behavioral science of mental disorders and aging. Dr. Necka has served as a representative to the Office of Behavioral and Social Sciences Research and the Basic Behavioral and Social Science Opportunity Network and coordinator of the NIH Intramural Affective Neuroscience Seminar. She received her PhD in psychology from the University of Chicago and completed her postdoctoral fellowship at the National Center for

Complementary and Integrative Health. Her research focused on the role of social and interpersonal factors on health and cognition and psychophysiological regulation of social behavior.

**Peter J. Neumann**, ScD, is Director of the Center for the Evaluation of Value and Risk in Health (CEVR) at the Institute for Clinical Research and Health Policy Studies at Tufts Medical Center, and Professor of Medicine at Tufts University School of Medicine. He is the founder and Director of the Cost-Effectiveness Registry, a comprehensive database of cost-effectiveness analyses in health care. Dr. Neumann has written widely on the role of clinical and economic evidence in pharmaceutical decision making and on regulatory and reimbursement issues in health care. He served as co-chair of the 2nd Panel on *Cost-Effectiveness in Health and Medicine*. He is the author or co-author of more than 300 papers in the medical literature and 3 books: *Using Cost-Effectiveness Analysis to Improve Health Care* (Oxford University Press, 2005); *Cost-Effectiveness in Health and Medicine, 2nd Edition* (Oxford University Press, 2017); *The Right Price: A Value-Based Prescription for Drug Costs* (Oxford University Press, 2021). Dr. Neumann has served as President of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR). He is a member of the Editorial Advisory Board of *Health Affairs* and the panel of health advisors at the Congressional Budget Office. He has also held several policy positions in Washington, including Special Assistant to the Administrator at the Health Care Financing Administration. He received his doctorate in health policy and management from Harvard University.

**Christine Nguyen**, MD, has been a caregiver for two parents with dementia. A multimedia journalist, she won an excellence award from the Asian American Journalists Association for her 2019 documentary exploring the relationship of war trauma, PTSD, and culture among Vietnamese Americans with dementia and their caregivers. She is a 2023 USC California Health Equity Reporting Fellow. More information about her work is at <https://www.christinenguyenmd.com>.

**Emerald T. Nguyen**, PhD, serves as a Social and Behavioral Science Administrator in the Population and Social Processes (PSP) Branch within the NIA Division of Behavioral and Social Research (BSR).

As a PSP Program Official, she primarily oversees NIA's macro-social trends in aging portfolio. Prior to joining NIA, Dr. Nguyen was a Data Scientist in the Division of Data Integration, Modeling, and Analytics at the National Institute of General Medical Sciences (NIGMS). She served as the lead analyst on the NIH Common Fund Diversity Program Consortium and conducted a range of analyses and evaluations of NIGMS-supported programs. From 2017 to 2019, Dr. Nguyen was an AAAS Science & Technology Policy Fellow in BSR at NIA. Prior to that, Dr. Nguyen was an AAAS Congressional Fellow sponsored by the American Sociological Association. While in Congress, she worked on health care policy issues and legislation. Dr. Nguyen completed her PhD in sociology at the University of California, Davis.

**Petra Niles**, MSG, is a Gerontologist and current Senior Manager of African American Services at Alzheimer's Los Angeles. She has been with the organization for more than 11 years and has an extensive background in aging issues such care management, elder abuse, program development, curriculum development, strategic partnerships, and the larger community. Ms. Niles currently provides ongoing education and outreach in the Los Angeles area as well as implements culturally specific workshops to the African American community in collaboration with faith-based institutions. Many of her efforts are focused on improving services to persons with dementia, their families, and caregivers particularly through the West Central-South Central Dementia Care

Network, which she coordinates. By bringing together community members and professionals from various agencies, Ms. Niles seeks to increase awareness of Alzheimer's disease and improve service delivery. She also believes strongly in the importance of motivating young people to better understand and become active in the fight against Alzheimer's disease.

**\*Priscilla Novak**, PhD, MPH, manages a health services research portfolio within the Division of Behavioral and Social Research, Population and Social Processes Branch. Dr. Novak's federal career began at AHRQ, where she worked on a variety of health systems' topics including health IT, dissemination of Patient-Centered Outcomes Research findings in women's health, and teamwork training. In 2020 she led the award of the "Accelerating Change and Transformation in Organizations and Markets" contract to enable field-based health services research. Her career includes roles at the National Cancer Institute, Office of Personnel Management, Leading Age, the Association of American Medical Colleges, Dell (contract with HHS' Office on Women's Health), and the Peace Corps in Bolivia. Her published research covers a range of topics including racial and ethnic health disparities, local health departments, and substance use and mental health.

Dr. Novak received her PhD in health services from the University of Maryland and a master of public health from George Mason University.

**Lisa Onken**, PhD, directs the Behavior Change and Intervention program in the NIA Division of Behavioral and Social Research. She joined NIA in 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. Dr. Onken received her PhD in clinical psychology from Northwestern University. Prior to joining NIH she held a variety of academic, clinical, and research scientist positions at Northwestern University, the University of Illinois Medical Center, and the Walter Reed Army Institute of Research.

At NIA, Dr. Onken administers a broad program of research on the development of behavioral interventions to promote the health and well-being of individuals as they age, including research on interventions to promote positive affect, reduce negative affect, foster sleep, and improve the emotional well-being and quality of life for those who provide care and for people who live with dementia. Using the NIH Stage Model, a comprehensive translational conceptual framework for principle-driven behavioral intervention development as a conceptual framework, she promotes the development of interventions that are maximally potent and scalable to reach those in need. In addition to leading the Roybal Translational Centers program, she is a Project Scientist on the NIH Science of Behavior Change Program and on the NIA AD/ADRD Health Care Systems Research Collaboratory.

**Van Ta Park**, PhD, MPH, is a Professor at the University of California, San Francisco (UCSF) School of Nursing and teaches in the Advanced Public Health Nursing program. Her primary research interest is addressing issues related to racial and ethnic minority health and health care disparities, especially among Asian American and Pacific Islander (AAPI) populations, through community-based participatory research. Her research areas include mental health and Alzheimer's disease and related dementias caregiving.

Her current work includes a NIH/NIA R24 grant, Collaborative Approach for AAPI Research and Education (CARE), which aims to address the gap and reduce disparities in research participation among AAPI populations. The multilingual CARE registry has more than 9,700 participants. Dr. Park also has a COVID-19 NIH/NIA administrative supplement, COVID-19 Effects on the Mental and Physical Health of AAPI Survey Study (COMPASS), which is a

national, multilingual survey that assesses the effects of COVID-19 on more than 5,000 AAPI participants. Dr. Park is a Multiple Principal Investigator for a R56 NIH/NIA grant called Asian Cohort on Alzheimer's Disease (ACAD), which is an international collaboration with the goal of compiling a robust sample size of Asian American and Canadian subjects for Alzheimer's disease research.

Dr. Park is the PI for a PCORI community engagement-dissemination project, Koreans Invested in Making Caregivers Health Important (KIMCHI), which aims to help improve the knowledge, attitudes, and behaviors of Korean American caregivers and other stakeholders about dementia prevention/care, advanced care planning, and potential future PCORI participation.

Some of her past work included the Alzheimer's Association's Mentored New Investigator Research Grant to Promote Diversity. The purpose of this randomized controlled trial was to evaluate the effectiveness of a culturally tailored bilingual program in reducing stress and depression among Vietnamese American dementia caregivers.

**\*Kate Possin**, PhD, is a Professor of Neurology at UCSF and the Global Brain Health Institute. Dr. Possin's research program is focused on improving the detection, diagnosis, and care for people with neurodegenerative disease. She is the project lead of TabCAT, a software platform for tablet-based cognitive testing frequently used in research studies and clinical services. The Brain Health Assessment is a 10-minute assessment on TabCAT designed for the detection of cognitive impairment in everyday clinical settings. She is also the PI of the Care Ecosystem, a telephone-based supportive care program for persons with dementia and their caregivers.

Dr. Possin was awarded her PhD in clinical psychology from UCSD. During her training at UCSD, she studied cognitive changes associated with Parkinson's disease. She completed her internship in clinical neuropsychology at UCSF in the departments of psychiatry and neurology and did her postdoctoral fellowship in the UCSF Department of Neurology. She currently holds the John Douglas French Alzheimer's Foundation Endowed Professorship and is a professor in residence in the Department of Neurology.

**Jennifer M. Reckrey**, MD, is an associate professor in the Department of Geriatrics and Palliative Medicine at the Icahn School of Medicine at Mount Sinai. She is a health services researcher and geriatrician who provides primary care to people at home as part of the Mount Sinai Visiting Doctors Program.

Dr. Reckrey's research explores the ways in which home-based models of clinical and long-term care support people with dementia and other serious illnesses living in the community. In particular, she is interested in the role that paid caregivers like home health aides and personal care attendants play in the home-based dementia care team and how this direct care matters for care recipients, their families, and the health care system. She was awarded the Dan Gilden Creative Investigator Award by the American Academy of Home Care Medicine in 2021 in recognition of her innovative approach to studying full spectrum of care, services, and supports that enable those with functional impairment to remain living at home.

**Robert Reid** is a full-time care partner to his wife Kimberly who was officially diagnosed with Early Onset Alzheimer's on June 15, 2017, after having memory issues for 2 years prior to her diagnosis. In addition to sitting on the Alter Advisory Board, Mr. Reid also facilitates the National Council of Dementia Minds' Black Dementia Minds support group for those currently living with dementia. He and Kimberly live in Hampton, Georgia, and have two wonderful young adult children.

**Siobhan Reilly**, PhD, is a Professor and the Director of Applied Dementia Studies at the University of Bradford. Dr. Reilly's background is in applied health and social care research. Her research is primarily concerned with improving the evidence base for the delivery of health and social care services for people with dementia, older people with long-term conditions, and people with severe mental illness. Her work includes the policy, practice, organization, and delivery of health and social care services, particularly in relation to the integration and coordination of services. Dr. Reilly has worked with a wide network of researchers, health/social care/third sector decision and policy makers and has experience in leading mixed method health and social care research studies and evaluations using a range of methods.

**Jason Resendez** is the President and CEO of the National Alliance for Caregiving (NAC), where he leads research, policy, and innovation initiatives to build health, wealth, and equity for America's 53 million family caregivers. Prior to joining NAC, Mr. Resendez was the founding Executive Director of the UsAgainstAlzheimer's Center for Brain Health Equity and was the PI of a \$1.5 million Healthy Brain Initiative cooperative agreement with CDC. While at UsAgainstAlzheimer's, he pioneered the concept of Brain Health Equity through peer-reviewed research, public health partnerships, and public policy. His efforts to champion health and racial justice for patients and caregivers have earned national recognition and in 2020, he was named one of America's top influencers in aging by PBS's Next Avenue alongside Michael J. Fox and Surgeon General Dr. Vivek Murthy. Mr. Resendez received the LULAC Presidential Medal of Honor and the HerMANO Award from MANA—A National Latina Organization—for his advocacy on behalf of the Latino community.

**David B. Reuben**, MD, is the Archstone Foundation Professor at the David Geffen School of Medicine at UCLA, where he serves as Director, Multicampus Program in Geriatrics Medicine and Gerontology; Chief, Division of Geriatrics; and Director of the UCLA Alzheimer's and Dementia Care program.

Dr. Reuben sustains professional interests in clinical care, education, research, and administrative aspects of geriatrics, maintaining a clinical primary care practice of frail older persons and attending on inpatient and geriatric psychiatry units at UCLA. His bibliography includes more than 265 peer-reviewed publications in medical journals, 45 books, and numerous chapters. He is PI of D-CARE, the Dementia Care Study.

Dr. Reuben is the lead author of the widely distributed book, *Geriatrics at Your Fingertips*. He is a past President of the American Geriatrics Society and the Association of Directors of Geriatric Academic Programs. Dr. Reuben served for 11 years on the Geriatrics Test Writing Committee for the American Board of Internal Medicine (ABIM) and for 8 years on the ABIM's Board of Directors, including as Chair from 2010 to 2011. He is a member of the National Advisory Committee on Aging for the NIA.

**Maricruz Rivera-Hernandez**, PhD, is an Assistant Professor of Health Services, Policy and Practice at Brown University. Dr. Rivera-Hernandez is a gerontologist and health services researcher deeply committed to a career in health and health care disparities research, examining disparities for vulnerable older adults, and an advocate of diversity and inclusion. Her goal is to develop and test interventions that will improve care and decrease any disparities detected.

Dr. Rivera-Hernandez completed an AHRQ T32 fellowship at the Center for Gerontology at Health Care Research at Brown University. After her fellowship, she wrote and received an NIA Diversity Supplement to support her research related to health care access and disparities in quality of care among Medicare beneficiaries.

Dr. Rivera-Hernandez has done extensive research regarding Medicare enrollees. Her current research agenda focuses on identifying strategies for more efficient and effective health care access, delivery, and continuity of care among older adults, including people with ADRD and other complex conditions. She has received different sources of funding from NIH, including a NIA R03 to identify disparities in short- and long-term care use among people with and without ADRD; a translational research grant to explore health care choices among vulnerable groups with and without ADRD; and a K01 award to study Medicare Advantage plan choice and selection among Black and Hispanic Medicare enrollees and low-income older adults with ADRD.

**Karen A. Roberto**, PhD, is a University Distinguished Professor, Senior Fellow at the Center for Gerontology, and the Executive Director of the Institute for Society, Culture and Environment at Virginia Tech. Dr. Roberto's research program focuses on health and social support in late life and includes studies of the daily lives of rural older women with chronic health conditions, dementia family caregiving, and elder abuse. Much of her research relies on the construction of surveys for use with community-based samples, combines quantitative and qualitative methodologies, and includes interviews with older adults, family members, and formal service providers. She is the author of more than 225 scholarly articles and book chapters and the editor/author of 15 books. Dr. Roberto led the first longitudinal study of caring for persons diagnosed with MCI, which contrary to beliefs held at the time, showed that MCI affected all aspects of daily functioning of not only the person living with MCI, but also the family member who assumed responsibility for their care. Her current research includes federally funded studies of the service needs of family caregivers living in rural, often underserved geographic areas; dementia family caregiving in rural Appalachia during the COVID-19 pandemic; and the daily experiences of extended family caregivers (e.g., grandchildren, siblings, nieces/nephews) of PLWD. Dr. Roberto is a fellow of the American Psychological Association, the Gerontological Society of America, the Association for Gerontology in Higher Education, and the National Council on Family Relations.

**Tina Sadarangani**, PhD, RN, ANP-C, GNP-BC, is an Assistant Professor in the Rory Meyers College of Nursing at New York University (NYU). Dr. Sadarangani is an NIH-funded PI and board-certified primary care nurse practitioner. She is cross-appointed as an Assistant Professor in the NYU School of Medicine Department of Population Health. Her program of research is underscored by a profound commitment to advancing the health of minoritized older adults by leveraging the strengths of community-based adult day health care centers to target health disparities. In the past 3 years, she has expanded her program of research to focus on identifying and addressing the health care needs of cognitively impaired older immigrants by using the adult day health center as a platform for the delivery of culturally and linguistically congruent care. Her ongoing collaborations with the California Association of Adult Day Services, as well as other community-based organizations, have demonstrated that integrating adult day centers into the health care continuum contributes to reductions in avoidable health care utilization.

Dr. Sadarangani's latest work focuses on improving communication between adult day centers and primary care providers using low-cost mobile technology. She recently received a K23 Career Development Award as well as an R21 from NIA. She previously received a Career Development Award from the NIA IMPACT Collaboratory, and currently serves as an Adjunct Professor and member of the Collaboratory's Patient and Caregiver Relevant Outcomes (PCRO) core. She holds prior degrees from Georgetown University (anthropology), the University of Pennsylvania (MSN), and NYU Meyers (BSN, PhD).

**Marcel Salive**, MD, MPH, is a Health Scientist Administrator within the NIA Division of Geriatrics and Clinical Gerontology. Dr. Salive administers the research portfolio on multiple chronic conditions' treatment and prevention, polypharmacy and deprescribing within NIA's Division of Geriatrics and Clinical Gerontology. He developed initiatives on pragmatic clinical trials, including treatment of comorbid conditions in persons with ADRD.

He earned chemistry and medical degrees from the University of Michigan and completed his preventive medicine residency and a master's in public health at Johns Hopkins University. From 1990 to 1995, he was a senior investigator in the NIA intramural program.

Subsequently he has held leadership positions at CMS, the National Heart, Lung and Blood Institute, and FDA. He previously served as Director of the Division of Medical and Surgical Services within the Coverage and Analysis Group of CMS and was responsible for developing and maintaining national coverage decisions for Medicare beneficiaries using a rigorous and open evidence-based process. His work in developing Medicare coverage of new and innovative services was recognized with the PHS Meritorious Service Medal. He has developed and led research initiatives in several areas including outcomes research, Alzheimer's disease etiology and diagnosis, vaccine safety, and translation of clinical research into primary care practice.

**Raj C. Shah**, MD, is a Professor of Family and Preventive Medicine and the Co-Director of the Center for Community Health Equity with the Rush Alzheimer's Disease Center. After completing a family practice residency at West Suburban Hospital and Medical Center in Oak Park, Illinois, he received further training in geriatrics at Rush University. Dr. Shah's academic career interest is the design and conduct of community-based clinical trials for the prevention and treatment of age-related conditions including memory loss. He is a PI for clinical trials in Alzheimer's disease and other common age-related conditions, some of which are focused on caregiver interventions. He also provides or has provided support for longitudinal research and infrastructure projects on memory and aging, including the Rush Alzheimer's Disease Research Core Center, the Rush Alzheimer's Disease Assistance Center, the Rush Memory Clinic Data and Specimen Repository, and the CATCH-ON Geriatric Workforce Enhancement Program. Dr. Shah is a co-leader of the Illinois Cognitive Resources Network, which oversees efforts for Dementia Friendly Illinois, Dementia Friends Illinois, and ILBrainHealth.org. He is co-host of a podcast (The Brain Trust) developed by the Illinois Academy of Family Physicians and the Illinois Department of Public Health to promote early detection of dementia.

**\*Joanne Spetz**, PhD, is a Professor, Director, and Brenda and Jeffrey L. Kang Presidential Chair in Health Care Financing at the Philip R. Lee Institute for Health Policy Studies (IHPS), UCSF. IHPS is a 50-year-old research unit that conducts innovative research to support, guide, and enable policy makers, communities, and clinicians in making evidence-informed decisions that improve health and health care for individuals and families.

Dr. Spetz's research focuses on the economics of the health care workforce, organization of health care services, and quality of health care. She directs the federally funded UCSF Health Workforce Research Center on Long-Term Care, which generates evidence to ensure an adequate workforce to provide patient-centered care to individuals with long-term care needs across the lifespan, and the NIA-funded Advancing Workforce Analysis and Research for Dementia (AWARD) Network, which seeks to advance research on the workforce that serves PLWD by building a community of scholars and activities to support them. She is an internationally known expert on the nursing workforce, leading studies of nurse supply, demand, education, earnings, and contributions to the quality of care across health care settings. Dr. Spetz is an Honorary Fellow of the American Academy of Nursing.

She was a member of the NASEM Committee on Consideration of Generational Issues in Workforce Management and Employment Practices and the Institute of Medicine Standing Committee on Credentialing Research in Nursing.

**\*Luke Stoeckel**, PhD, is a Program Director and Project Scientist in the NIA Division of Behavioral and Social Research, where he collaborates to advance fundamental understanding of brain-behavior relationships and the development and testing of neuropsychological assessments and interventions for early AD/ADRD. He emphasizes open science and DEIA principles (open, integrated, inclusive, accessible) in all his practices. Dr. Stoeckel is a licensed clinical neuropsychologist who specializes in human neuroscience, neuropsychological assessment and interventions, and behavior change research and clinical practice. He completed his undergraduate studies at Harvard College, his PhD in medical/clinical psychology at the University of Alabama at Birmingham, and his internship and postdoctoral training in clinical neuropsychology and cognitive neuroscience at Massachusetts General Hospital (MGH), McLean Hospital, the Massachusetts Institute of Technology (MIT), and Harvard Medical School (HMS). Prior to joining NIH, he was the Director of Clinical Neuroscience at the MGH Center for Addiction Medicine, Assistant Professor of Psychology at HMS, Affiliated faculty at the Martinos Center for Biomedical Engineering at MGH, and a Visiting Scientist at McLean Hospital and the McGovern Institute for Brain Research at MIT.

**Cassandra Thomas** is a Clinical Research Coordinator with the Gleason Research Group at the University of Wisconsin (UW) School of Medicine and Public Health focusing on Alzheimer's disease research in under-represented populations. Ms. Thomas grew up on the Oneida Nation reservation in Wisconsin and earned an undergraduate degree from UW-Madison and obtained a master's degree in sport science and rehabilitation from Logan University. Ms. Thomas served as a full-time care assistant to her maternal grandmother who was diagnosed with mixed dementia in late 2017 until her grandmother's passing in July 2022. She joined the Community Advisory Board of the Oneida Nation of Wisconsin in January 2022 to share her insights and advocate for Native American people living with ADRD.

**Jasmine L. Travers**, AGPCNP-BC, CCRN, PhD, RN, is an Assistant Professor of Nursing at NYU Rory Meyers College of Nursing. Her career is dedicated to designing and conducting research to improve health outcomes and reduce health disparities in vulnerable older adult groups using both quantitative and qualitative approaches. Her current work focuses on mitigating disparities in appropriate access and use of in-home and facility-based long-term care for older adults (i.e., home and community-based settings, nursing homes, and assisted living). Currently, Dr. Travers is the PI of a Robert Wood Johnson Foundation 4-year Career Development Award through the Harold Amos Medical Faculty Development Program, with which she is examining the association of neighborhood disadvantage with nursing home outcomes using large-scale nursing home data. She has also received a Paul B. Beeson Emerging Leader 5-year K76 Award through NIA, with which, in a mixed-method study, she will develop a survey instrument aimed to identify unmet needs that are disproportionately driving avoidable nursing home placements. Most recently, Dr. Travers served on the NASEM Committee on the Quality of Care in Nursing Homes, which on April 6, 2022, released the widely anticipated report titled *The National Imperative to Improve Nursing Home Quality*.

Dr. Travers has published widely on the topics of aging, long-term care, health disparities and inequities, workforce diversity and workforce issues, vaccinations, and infections. She received her PhD from Columbia University School of Nursing.

**Courtney Van Houtven**, PhD, MSc, trained as a health economist, is a Research Career Scientist at the Center of Innovation to Accelerate Discovery and Practice Transformation (ADAPT), Durham Veterans Affairs Health Care System. She is also a Professor of Medicine in the Department of Population Health Science at Duke University School of Medicine. Her research examines how family caregiving affects economic, health, and health care outcomes of care recipients and caregivers. She is assessing the negative economic spillovers for caregivers of advanced cancer patients, including out-of-pocket costs, work changes, and debt accumulation (R01 NCI: Siminoff, PI). Dr. Van Houtven is also interested in understanding how to best support family caregivers through pragmatic trials and strategies, including through better inclusion of caregivers as explicit members of the health care team. She strives to evaluate promising models of care, including how home-and community-based services can preserve independence such as a geriatric primary care medical home model compared to usual primary care (IIR co-PI Nicki Hastings: 2017-2022). She directs the VA-CARES Partnered Evaluation Center, an ongoing national evaluation of the VA's Caregiver Support Program (2014-2027) to rigorously assess how supports and services affect caregiver and Veteran quality of life, economic security, and health system outcomes. She is co-PI on the QUERI Program Project, "Optimizing Function and Independence" (2016-2025), in which she worked with operational partners, clinical field staff, and a multidisciplinary research team to implement a family caregiver skills training curriculum nationally in VA (120 sites, 1,900 caregivers trained). In a new R-01 from NIA/NIH she is working with a team to develop a person-centered measure of home time for PLWD and their spousal caregivers (2021-2026) and will use machine learning to identify risk factors that interrupt the ability to remain in one's own home.

**Rachel M. Werner**, MD, PhD, is the Executive Director of the Leonard Davis Institute of Health Economics. She is Professor of Medicine at the University of Pennsylvania Perelman School of Medicine as well as the Robert D. Eilers Professor of Health Care Management and Economics at the Wharton School and a physician at the Philadelphia VA.

Dr. Werner's research examines the effects of health care policies on health care delivery, using methods designed to draw causal inference from observational data. She investigates the role of health care financing and payment in health care organization and delivery, and their impact of health equity. Her research has been published in leading peer-reviewed journals, in medicine, health policy, and health economics. Beyond publication, Dr. Werner has influenced research and policy as a member of numerous advisory committees to the state and federal government as well as research foundations.

Dr. Werner has received numerous awards for her work, including the Alice Hersh New Investigator Award from AcademyHealth, the Presidential Early Career Award for Scientists and Engineers, and the American Federation of Medical Research (AFMR) Outstanding Investigator Award. She is an elected member of the National Academy of Medicine.

She received her medical degree and doctoral degree in health economics from the University of Pennsylvania.

**Martha Williams**, MS, MFT, nindizhinikaaz (my name is). Makowaadiziikwe nindigoo ojibwemong (My Ojibway name translated in English is Woman with the strength of a bear.) Makwa nindoodem (My clan is Bear). I am an enrolled member of the White Earth Tribal Nation. I am the very proud mother of three boys. The eldest daughter and caregiver to my parents. My mom has Alzheimer' and my dad a disabled Vietnam Vet.

I have lived and worked on the White Earth Reservation for most of my life. I have a bachelor's in human services/business management and a master's in marriage and family Therapy.

My passion is development of our communities and addressing the needs of the community members. Addressing the many health disparities is imperative to the success of better living for the community. My passion in life is to give back to our underserved populations.

**\*Julie M. Zissimopoulos**, PhD, is a Professor in the USC Sol Price School of Public Policy. In addition to her faculty appointment, she is a Senior Fellow and Co-Director of the Aging and Cognition Research Program and Research Training at the Schaeffer Center for Health Policy and Economics. She is Director of USC's Resource Center for Minority Aging Research and Center for Advancing Sociodemographic and Economic Study of Alzheimer's Disease and Related Dementias (CeASES-ADRD), both focused on reducing burden of Alzheimer's disease and funded by NIA.

Dr. Zissimopoulos' current research focuses on economic costs of dementia, impacts of dementia on care partners, the use of and response to drug therapies for non-dementia conditions that influence risk of dementia; racial and ethnic disparities in diagnosis and health care treatment for dementia; and population measures of dementia using Medicare claims and survey data.

Dr. Zissimopoulos received her BA from Boston College, her MA from Columbia University, and a PhD in economics from UCLA.

## Stakeholder Engagement Panel

### Overview

As part of the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers (“The Summit”), NIA convened a Stakeholder Engagement Panel to solicit feedback from a variety of formal dementia care and caregiving stakeholders, including direct care workers, health services providers, patient advocates, payer representatives, and researchers. The overarching purpose of the Stakeholder Engagement Panel was to further a key goal of The Summit: To identify remaining unmet research needs with input from the research community, PLWD and their care partners, those who provide health care or services and supports to PLWD, and other stakeholders. PLWD refers to persons living with cognitive symptoms including MCI or diagnosed dementia.

### Panel Members

#### *Facilitator*

**Heidi Gil**, Chief Strategy Officer, LiveWell; Executive Committee Member, Stakeholder Engagement Team, NIA IMPACT Collaboratory

### Stakeholders

**Rajiv Ahuja**, JD, Associate Director, Milken Institute Center for the Future of Aging

**Alicia I. Arbaje**, MD, MPH, PhD, Associate Professor of Medicine, Johns Hopkins University School of Medicine

**Malaz A. Boustani**, MD, MPH, Richard M. Fairbanks Professor of Aging Research

**Ian N. Kremer**, JD, Executive Director, LEAD Coalition (Leaders Engaged on Alzheimer’s Disease)

**Dawn Lambert**, Co-leader of the Community Options Unit – Connecticut Department of Social Services

**Melissa Myers-Bristol**, MPA, Assistant Director at Clayton County Senior Services Department

**Petra Niles**, MSG, Gerontologist and Senior Manager of African American Services at Alzheimer’s Los Angeles

**Susan Peschin**, MHS, President and CEO, Alliance for Aging Research

**Jason Resendez**, President and CEO, National Alliance for Caregiving

**Sarah Sjöström**, MSN, RN, ACNP-BC, Associate Chief Nursing Officer, Hebrew Rehabilitation Center, Dedham

**Alicia Villegas**, LCSW, Director of Early Stage Services at Alzheimer’s Los Angeles

## Lived Experience Panel

### Panel Overview

As part of the 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers (“The Summit”), NIA convened a Lived Experience Panel to solicit feedback from PLWD and care partners/caregivers of PLWD. PLWD refers to persons living with cognitive symptoms including MCI or diagnosed dementia. The purpose of the Lived Experience Panel was to further one of the key goals of The Summit: To identify remaining unmet research needs with input from the research community, PLWD, and their care partners, those who provide health care or services and supports to PLWD, and other stakeholders.

### Panel Members

#### *Facilitators*

**Gary Epstein-Lubow**, MD, Associate Professor of Psychiatry and Human Behavior, Associate Professor of Medical Science, Alpert Medical School of Brown University; Associate Professor of Health Services, Policy and Practice, Brown University School of Public Health; Team Leader, Stakeholder Engagement Team, NIA IMPACT Collaboratory

**Monica Moreno**, Senior Director, Care and Support, Alzheimer’s Association

#### *Panelists*

**Dave Arnold**

**Willetha Barnette**

**Dr. Leslie Burger**

**Roberta Cruz**

**LuPita Gutierrez-Parker**

**Reda Harrison**

**Priscilla Jean-Louis**

**Deborah Jobe**

**Jim Mangi**