



The 2021 Conference on
**Engaging Family and
Other Unpaid
Caregivers of Persons
with Dementia in
Healthcare Delivery**

Online Appendix
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Ronald D. Adelman, M.D. is the Emilie Roy Corey Professor in Geriatrics and Gerontology and is Co-Chief of the Division of Geriatrics and Gerontology at the Weill Medical College of Cornell University and New York Presbyterian Hospital. Dr. Adelman directs Adult Palliative Medicine at Weill Cornell New York Presbyterian Medical Center. He is also the Executive Director of the Irving Sherwood Wright Center on Aging and Co-Director of the Cornell Center for Aging Research and Clinical Care. Dr. Adelman's research focuses on older patient-physician communication, caregiving, and issues in palliative medicine and hospice care.

Lauren Bangerter, Ph.D. is a health services researcher and gerontologist, focused on optimizing healthcare for older adults. She leads OptumLabs research program on Healthy Aging. Before joining OptumLabs, Lauren was a Research Associate at Mayo Clinic within the Division of HealthCare Policy and Research where she led research aimed at optimizing healthcare delivery for older adult patients and their family caregivers.

Arlene S. Bierman, M.D., M.S., is director of AHRQ's Center for Evidence and Practice Improvement which consists of five divisions the consisting of five divisions the Evidence-Based Practice Center Program; the U.S. Preventive Services Task Force Program; Digital Healthcare Research; Practice Improvement; Healthcare Delivery and Systems Research; as well as the National Center for Excellence in Primary Care Research. Dr. Bierman is a general internist, geriatrician and health services researcher whose work has focused on improving access, quality and outcomes of health care for older adults with chronic illness in disadvantaged populations and has published widely in these areas. Previously as a tenured professor she held appointments Health Policy, Evaluation, and Management; Public Health; and Medicine; and Nursing at the University of Toronto, where she was the inaugural holder of the Ontario Women's Health Council Chair in Women's Health.

Ginny Biggar is Executive Director of Communities at UsAgainstAlzheimer's. She leads UsA2's A-LIST registry and What Matters Most Insights research program investigating the needs and priorities of people living with dementia and family caregivers. Previously, she launched several advocacy coalitions – UsA2's Activists, Clergy and Veterans Networks, and Faith United Against Alzheimer's Coalition, and manages UsA2's longtime Facebook caregiver support group. Ginny was a caregiver for her father, who lived for decades with Multiple Sclerosis.

Rachel F. Bloom, M.S. is a third-year doctoral student in Applied Developmental Psychology at Fordham University. Her recent research has centered on identifying facilitators and barriers to advance care planning engagement among adult children of people experiencing cognitive decline, while her other interests include enhancing well-being for people with dementia and their families and psychologically supporting patients navigating medical systems. Rachel earned her MS in Bioethics from Columbia University in 2016 and her ScB from Brown University in 2013.

Sharon Brangman, M.D. is a SUNY Distinguished Service Professor and is the Inaugural Chair of the Department of Geriatrics at SUNY Upstate Medical University. Prior to this appointment, she had been the Division Chief of Geriatrics for 20 years. Dr. Brangman is director of the Upstate Center of Excellence for Alzheimer's Disease, as well as the Nappi Longevity Institute. Dr Brangman was a member of the Board of Directors of the American Geriatrics Society for ten years, and completed terms as President and Chair of the Board.

Julia Burgdorf, Ph.D. is a Research Scientist at the Center for Home Care Policy & Research and Research Associate at the Johns Hopkins Bloomberg School of Public Health. Dr. Burgdorf's research harnesses population-based survey, assessment, and claims data to examine the impact of family caregiving on older adults' health care utilization, with a particular focus on the Medicare home health benefit. Currently, she is engaged in a series of projects aimed at improving provider-led support for family caregivers assisting persons with dementia during home health care.

Josh Chodosh, M.D. is the inaugural endowed Michael L. Freedman Professor of Geriatric Research, Professor of Medicine and Population Health at the NYU Grossman School of Medicine, and Director of the Division of Geriatrics and Palliative Care at NYU. While at UCLA, Dr. Chodosh built a research career in dementia health services and developed a nationally recognized VA telehealth program in dementia care. In 2015, Dr. Chodosh joined NYU and launched the Freedman Research Center on Aging, Technology and Cognitive Health. He is a Core leader in NYU's National Institute on Aging's Alzheimer's Disease Research Center and Co-Leader of the CDC BOLD Public Health Center of Excellence on Early Detection of Dementia. Dr. Chodosh also co-founded the NYU Aging Incubator, a growing University-wide educational and research collective serving the larger University community.

Rita Choula, MA. is the Director of Caregiving with the AARP Public Policy Institute which bridges policy and research to practice, using an interdisciplinary approach that seeks to identify and address the unique diversity of family caregiving experiences, particularly those representing Black, AAPI, and Latino communities. In partnership with clinical experts, community organizations, and other key stakeholders, Rita develops and equips health care professionals with tools and resources that reflect and address the lived experience and many intersecting issues, often rooted in systemic injustice, that impact family caregiver experiences across settings. Moved by her personal experience serving as a family caregiver for her mother and grandmother, Rita is driven to ensure systems are structured in a holistic way that are inclusive of family caregivers, address their unique experiences, and enable them to manage their own wellbeing as well as that of those they care for.

Verena Cimarolli, Ph.D. is director of health services research and partnerships in the Washington, DC, office of the LeadingAge LTSS Center @UMass Boston. She holds a doctoral degree in applied developmental psychology from Fordham University. Dr. Cimarolli's research focuses on the psychosocial challenges experienced by older adults due chronic illness, their adaptation to these challenges, and the role of family/friend and formal caregivers in the process. Her research also identifies best strategies and interventions for supporting older adults with chronic illness and their caregivers in the context of long-term services and supports (LTSS).

Peggye Dilworth-Anderson, Ph.D. is a member of the faculty in Health Policy & Management at the Gillings School of Global Public Health, University of North Carolina- Chapel Hill. Her research focus is on health disparities and Alzheimer's disease with an emphasis on building knowledge for the scientific and lay community to inform conducting culturally relevant research and disseminating information about Alzheimer's disease and related disorders in medically underserved diverse populations.

Chanee Fabius, Ph.D, MA. is an Assistant Professor in the Department of Health Policy and Management at the Johns Hopkins Bloomberg School of Public Health. Dr. Fabius conducts research to improve aging and disability policy while supporting health equity for older adults, caregivers, and the direct care workforce. Her current projects (1) assess the role of the long-term services and supports environment in older adult and caregiver care experiences, and (2) examine strategies to better engage and integrate direct care workers in care delivery for older adults with dementia in the community. She completed a two-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.

Francesca Falzarano, Ph.D. is a Post-Doctoral Fellow in the Division of Geriatrics and Palliative Medicine at Weill Cornell Medicine. Her research focuses on stress and well-being in dementia family caregivers and her interests lie at the interface of technology and dementia care in support of patient and family caregiver health and well-being. Dr. Falzarano is currently working on a number of technology-based interventions targeting the improvement of psychosocial well-being in dementia care-partners and individuals with cognitive impairment. She is currently developing a web-based intervention to facilitate targeted assessment and formal service referrals based on areas of identified stress in dementia family caregivers, and is co-investigator on a study that seeks to develop and test a technology-based reminiscence therapy intervention for dementia patients and their family caregivers.

Esther Friedman, Ph.D. is a senior sociologist at the RAND Corporation where she also serves as director of the RAND Caregiving Initiative and co-organizer of the Aging, Disability, and Long-Term Care Strategy Group. Dr. Friedman works on a variety of topics related to long-term care and family caregiving. Her ongoing projects in this area examine the social support networks of family caregivers, the economic costs of family caregiving, and current and future kin availability for dementia care. Other recent work includes a study on the barriers and facilitators to integrating family caregivers into the health care team. Dr. Friedman earned a Ph.D. and M.A. in sociology from the University of California, Los Angeles, and an M.A. in statistics from Columbia University. Prior to joining RAND, she was a Robert Wood Johnson Foundation Health & Society Scholar at Harvard University.

William Haley, Ph.D. is a clinical psychologist who has worked with caregivers in diverse healthcare settings. He has also conducted research on caregiving for people with Alzheimer's disease, stroke, cancer, and terminal illness. This work has included studies of racial/ethnic diversity in caregiving, and development and evaluation of interventions for dementia and cancer caregivers. Dr. Haley is currently a Distinguished University Professor in the School of Aging Studies at the University of South Florida.

David W. Hancock, Ph.D. is a T32 Postdoctoral Fellow in the Division of Geriatrics and Palliative Care, in the Weill Department of Medicine at Weill Cornell Medical College. His research interests include the intersections of ageism, ADRD caregiving, and elder mistreatment and abuse, and intervention development to assist these populations. He is currently being mentored by Dr. Sara Czaja (WCM) and Dr. Karl Pillemer (Cornell).

Carl V. Hill, Ph.D, MPH, is the Chief Diversity, Equity and Inclusion Officer for the Alzheimer's Association®. Dr. Hill completed doctoral training at the University of Michigan and holds a master's degree in public health from Morehouse School of Medicine, and he received its Distinguished Alumnus Award in 2019.

Elissa Kozlov, Ph.D. received her doctorate in Psychology from Washington University in St. Louis with dual focuses in Clinical Psychology and Aging and Developmental Psychology. Following graduate school, she completed an internship in geropsychology at the Palo Alto Veterans Affairs Medical Center in Palo Alto, California. She then pursued a T32 fellowship at Weill Cornell Medicine in Behavioral Geriatrics. Dr. Kozlov's research focuses on innovative, non-pharmacological interventions for older adults with serious illness and their families. As part of this line of research, she piloted mHealth mindfulness therapy for caregivers of older adults with cognitive impairment and is planning to expand this area of research to investigate dyadic mHealth mindfulness for patients with serious illness and their caregivers.

Helen Lamont, Ph.D. is the Director of the Division of Disability and Aging Policy in the Office of Behavioral Health, Disability, and Aging Policy 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 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 has a portfolio of research on dementia, including a project to examine use of inpatient psychiatric facilities by people with dementia. Dr. Lamont also leads work on family and informal caregiving, and represents ASPE on the RAISE Family Caregiving Advisory Council. Dr. Lamont has worked across HHS 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.

Carol Levine, MA. is a senior fellow of the United Hospital Fund (UHF) and a writer, researcher, and consultant in family caregiving and health policy. She is the former director of UHF's Families and Health Care Project, Before joining UHF in 1996, she directed the Citizens Commission on AIDS in New York City from 1987 to 1991, and The Orphan Project, which she founded, from 1991 to 1996. As a senior staff associate of The Hastings Center, she edited the Hastings Center Report. Ms. Levine is the editor of *Living in the Land of Limbo: Fiction and Poetry about Family Caregiving* (Vanderbilt University Press, 2014). In 2014 she also published *Navigating Your Senior Years For Dummies* (AARP and Wiley, 2014; a portable edition was published in 2021). In 1993, Ms. Levine was awarded a MacArthur Foundation Fellowship for her work in AIDS policy and ethics.

Elizabeth Luth, Ph.D. is a Core Faculty member at the Institute for Health, Health Care Policy, & Aging Research and an Assistant Professor in the Department of Family Medicine and Community Health at Rutgers University. Her research focuses on identifying racial, ethnic, and socioeconomic disparities in end-of-life care and developing practical, inclusive, and scalable tools to reduce disparities and promote health equity. Dr. Luth currently holds an R00 from the National Institute on Aging. This project develops and pilot tests a training and tool for home hospice clinicians to improve care and support to patients with dementia and their families. In 2021, she completed a three-year NIA-funded T32 Postdoctoral Fellowship, followed by a one-year NIA-funded K99, in the Department of Geriatrics and Palliative Medicine at Weill Cornell Medicine. She received her PhD in Sociology from Rutgers University in 2017.

Katie Maslow, MSW, FGSA. is a visiting scholar at the Gerontological Society of America (GSA). The focus of her work is care-related issues for older people with cognitive impairment, dementia, and co-existing medical conditions and their family and other caregivers. Since 2015, she has worked with colleagues at the Benjamin Rose Institute on Aging and Family Caregiver Alliance to develop and disseminate the Best Practice Caregiving database. She was co-chair of the October 2017 National Research Summit on Care, Services and Supports for Persons with Dementia. Before joining GSA in 2016, Katie was a scholar-in-residence at the Institute of Medicine (IOM), National Academies of Science, in Washington DC, and previously conducted policy-related research for the Alzheimer's Association and the U.S. Office of Technology Assessment.

Mary S. Mittelman, is research professor of Psychiatry and Rehabilitative Medicine at NYU School of Medicine and the director of the NYU Alzheimer's Disease and Related Disorders Family Support Program, which was launched in 2016 with funding from New York State to provide comprehensive services to family caregivers of people with dementia. Trained in psychiatric epidemiology, she has been developing and evaluating psychosocial interventions for people with cognitive impairment and their family members for more than three decades. In the past few years, Dr. Mittelman has expanded her research focus to interventions that include the person with dementia with the family caregiver. She conducted an evaluation of the Meet Me at MoMA program, and is the founder of The Unforgettables, a chorus for people with dementia with their family members which rehearses and gives regular concerts in New York City.

Stephanie J. Monroe, JD. is Director of Equity and Access for UsAgainstAlzheimer's (UsA2) and Executive Director of its African American Network. UsA2 is a national advocacy organization raising awareness of the disparate impact of Alzheimer's on communities of color; promoting strategies to address AD health disparities; supporting greater minority participation in clinical trials and calling out the importance for underserved communities to adopt risk reduction strategies that promote brain health and healthy aging. An attorney with three decades of federal public policy experience, Stephanie has held senior staff positions in the U.S. Senate and served as Assistant Secretary for Civil Rights in the U.S. Department of Education from 2005-2009.

Dr. Linda Nichols, Ph.D. a medical anthropologist, is Co-Director of the VA's national Caregiver Center, located at the Memphis VA Medical Center. She is also Co-Director of the Caregiver Center at the University of Tennessee Health Science Center and Professor, Preventive Medicine. The VA Caregiver Center provides evidence-based interventions to caregivers of Veterans and develops and tests new interventions for caregivers. Both Centers provide training to staff and organizations across the country to implement caregiving interventions. Her current DoD-funded research focuses on interventions for caregivers of Veterans with traumatic brain injury and dementia.

Jennifer Olsen, M.P.H, Dr.P.H., an experienced epidemiologist, serves as Chief Executive Officer of the Rosalynn Carter Institute for Caregivers (RCI), which promotes the health, strength, and resilience of caregivers throughout the United States. Prior to joining RCI, Olsen managed the Ending Pandemics in Our Lifetime initiative at the Skoll Global Threats Fund, and prior to that she served as Fusion Division Director in the Office of the Assistant Secretary for Preparedness & Response at the U.S. Department of Health and Human Services, where she developed and implemented an analytics platform to increase awareness and information sharing during public health emergencies. She also previously held roles with the Defense Threat Reduction Agency, where she conducted scenario modeling. Olsen holds a B.A. in biomathematics from Rutgers University, an M.P.H. in Epidemiology from The George Washington University, and a Dr.P.H. from the University of North Carolina.

Veerawat Phongtankuel, M.D. is an Assistant Professor at Weill Cornell Medicine in the Department of Medicine. His research interests revolve around improving the quality of life for older adults and their caregivers by improving patient care and reducing caregiver burden and burdensome care transitions.

Karl Pillemer, Ph.D. is the Hazel E. Reed Human Development Professor at Cornell University, Professor of Gerontology in Medicine at Weill Cornell Medicine, and Director of the Cornell Institute for Translational Research on Aging. His major interests center on human development over the life course, with a special emphasis on family and social relationships in middle age and beyond. An ongoing program of research focuses on the nature and dynamics of family caregiving for impaired older people, which he has been carrying out over the past two decades with funding from the National Institutes of Health and other sources. He also conducts research long-term care for older people, and on elder mistreatment. His overall focus is on translational research, exploring ways to speed the transfer of findings from basic research into scientifically tested interventions.

Steven Starks, M.D. is a geriatric psychiatrist and clinical assistant professor at the University of Houston College of Medicine. His work aims to address racism and inequity in medical education, organized medicine and mental health. Prior to his current role he was a Health and Aging Policy Fellow/American Political Science Association Congressional Fellow and contributed to the design, drafting and roll out of the Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3) – the first comprehensive policy proposal to empower the Secretary of Health and Human Services to directly negotiate the price of prescription drugs.

Madeline Sterling, M.D. is an Assistant Professor of Medicine in the Department of Medicine at Weill Cornell Medicine. She is a practicing general internist and a health services researcher. The focus of her research is to improve healthcare delivery for adults with cardiovascular disease and keep them at home with optimal quality of life. In partnership with home care agencies and worker unions, she aims to design, test, and implement novel interventions that leverage home health aides to improve healthcare delivery for adults with cardiovascular disease and eventually other chronic diseases.

Alan Stevens, Ph.D., M.S. is the Director of the Center for Applied Health Research at Baylor Scott and White Health (BSWH) where he also holds the Vernon D. Holleman-Lewis M. Rampy Centennial Chair in Gerontology. Dr. Stevens is a highly regarded and respected leader within the field of gerontology. With over 25 years' experience in academic medical schools and a leading integrated health care organization, he has made significant contributions to the fields of dementia care, family caregiving, care transitions, and management of chronic diseases. His projects are person- and family-centered and built on partnerships between healthcare organizations and community-based organizations with a focus on outcomes that are meaningful to the multiple stakeholders engaged in promoting the health of older adults.

Robyn I. Stone, DrPH. Senior Vice President for Research at LeadingAge and Co-Director of the LeadingAge LTSS Center @UMass Boston, is a noted researcher and internationally recognized authority on long-term care, aging services and workforce policy. She has been engaged in policy development, program evaluation, large-scale demonstrations and other applied research activities in these areas for over 40 years. Dr. Stone has held senior research and policy positions in both the federal government and the private sector, including serving in the U.S. Department of Health and Human Services as Deputy Assistant Secretary for Disability, Aging and Long-term Care Policy and Assistant Secretary for Aging in the Clinton administration. Her work bridges the worlds of research, policy and practice to improve the care delivered to older adults--particularly lower-income populations—and to ensure the best quality of life for these individuals and their families.

C. Grace Whiting is the President/CEO of the National Alliance for Caregiving, a 501(c)(3) nonprofit organization dedicated to building partnership in research, advocacy, and innovation to make life better for family caregivers. An attorney by background, Grace has more than ten years of experience working health and aging policy in Washington, DC. To learn more about the National Alliance for Caregiving, visit www.caregiving.org.

Julie M. Zissimopoulos, Ph.D. is Associate Professor in the Sol Price School of Public Policy and Senior Fellow, Director of Aging and Cognition Research Program at the Schaeffer Center for Health Policy and Economics, both at the University of Southern California (USC). 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 the National Institute on Aging. Dr. Zissimopoulos employs the methods of empirical economics to the study of costs of dementia; drug therapies for non-dementia conditions that influence risk of dementia; racial and ethnic disparities in health of care partners and diagnosis and health care for dementia; and population measures of dementia using Medicare claims and survey data.