National Dementia Care Collaborative (NDCC)

Autumn Summit > November 19, 2024

Presenters

David Bass, PhD, Bass is Senior Vice President, Senior Research Scientist and Director of the Benjamin Rose Institute on Aging. He has led over 80 funded research projects on topics such as: coping with chronic illness; family caregiving; quality of care and services; dementia and dementia care; and use and impact of formal services and informal support. Results of these investigations have been widely published and used to develop innovative programs such as BRI Care ConsultationTM. His current research focuses on development, testing and broad-scale implementations of evidence-based programs, with a special emphasis on care for persons with Alzheimer's disease or other dementias and their family caregivers.

Malaz Boustani, MD, is Chief Innovation and Implementation Officer at Indiana University Center for Health Innovation and Implementation Science. Dr. Boustani is a geriatrician, neuroscientist, and implementation scientist with extensive experience in developing, evaluating, implementing and disseminating healthcare innovations focusing on brain health. He has built a clinical laboratory of more than 2,000 ambulatory practices serving at least 10 million lives across five Midwestern States. To detect cognitive impairment, reduce exposure to potentially harmful medications and procedures, and enhance the recovery of brain health after critical illness, he developed a combined human- and computer-based decision support system. He contributed to the identification of acute and chronic adverse cognitive effects of medications and developed the anticholinergic cognitive burden scale. His Aging Brain Care model in primary care achieves the quadruple aim of improving brain health, improving brain care and reducing cost with enhanced patient and clinician experiences, and has become the standard of brain care across the world.

Bart Brammer was diagnosed with Alzheimer's disease in 2020 at the age of 70. He lives with his partner Darlene in Seymour, Tennessee near the Smoky Mountains and has three adult daughters living in Indiana. Bart was a car builder and corporate trainer for 30-plus years after serving in the Army Security Agency during the Vietnam War. Early in 2020, Bart became concerned when he was having difficulty keeping up with his work travel schedules. After suffering from a stroke during a work trip, the effects left Bart with temporary gait issues, a stutter, and forgetfulness. When the forgetfulness did not abate after recovery, an MRI and PET scan confirmed his diagnosis of Alzheimer's disease. Bart received his diagnosis from a nurse practitioner, not his doctor. They spent an hour discussing potential medications to address his symptoms and the important steps to think about in the wake of a diagnosis. Bart felt he needed more information and said "It was a difficult time. I was depressed and in a state of denial." He soon realized, however, that his secret and the stigma of Alzheimer's were holding him back. Bart quit his training job and began volunteering at museums, nature







centers, and later, Alzheimer's Association and Alzheimer's Tennessee. Bart said "I am focused on completing my bucket list now, while I can still enjoy life. By being fully engaged, I am taking the future burden off of my family and making sure that my preferences are heard."

Carolyn Clevenger, DNP, is a gerontological nurse practitioner and Professor at the Nell Hodgson Woodruff School of Nursing at Emory University. She is a Fellow of the American Association of Nurse Practitioners, the Gerontological Society of America, and the American Academy of Nursing. Her research focuses on the geriatric nurse practitioner workforce, psychoeducation programs for dementia family caregivers, and new models of care. Clevenger is the founder and director of Emory Nursing's Integrated Memory Care practice. The IMC is a nurse-led primary care practice for people living with dementia with a clinic location as well as senior living community programs across metro Atlanta.

Roberta Cruz was a caregiver to her mother, Zenaida Cruz, for 9 years, coinciding with her own experience of new motherhood. Ms. Cruz's mother first started exhibiting noticeable symptoms of cognitive change in November 2014 during a visit in North Carolina. Before a formal diagnosis of Alzheimer's disease, Ms. Cruz moved her mother from California to live with her young family in North Carolina. As her mother's health declined, Roberta has navigated adult day programs, in-home care, residential care and in-home hospice care while simultaneously navigating the search for childcare, preschool and elementary school selection for her young children and moving across the country. Adding an additional layer to her experience as part of the "sandwich generation," she has charted a path that both embraces and challenges traditional Filipino expectations of daughters as caregivers. Grounded in gratitude to all those who have supported her and her young family along the caregiving journey, she spends time advocating for caregivers when available, in between teaching garden and cooking classes at her children's school and dance classes at the local YMCA.

Morgan Daven, MA, is Vice President, Health Systems, for the Alzheimer's Association. Mr. Daven leads the Association's Health Systems engagement, which is increasing access to timely diagnosis and quality care for millions of older Americans through partnerships with more than 350 health systems in the United States. In 2018 he established the Alzheimer's and Dementia Care ECHO® Program, which uses interactive, case-based learning to help care teams improve person-centered care in primary care and long-term care settings. Morgan has more than 25 years of experience in public health, previously leading primary care quality improvement for the American Cancer Society and helping to develop Project Access, a physician-led program for access to care replicated in over 50 communities in the United States.

Molly DeBrosse, LSW, is the Program Manager for Benjamin Rose Institute on Aging. She coordinates the licensing, implementation, and user support for Benjamin Rose's evidence-based and evidence-informed programs and product lines including BRI Care ConsultationTM, SHARE for Dementia, and Online Training for Mandated Reporters of Adult Abuse, Neglect, and Exploitation. She also assists with the expansion and implementation of evidence-based or evidence-informed programs that are in development.







Sarah Dulaney, RN, MS is a geriatric clinical nurse specialist and clinical director for the <u>Care Ecosystem</u> at the UCSF Memory and Aging Center. Sarah joined the Care Ecosystem team in 2014 and helped develop the Care Ecosystem care protocols, implementation toolkit, caregiver education materials, and online care navigator training program. In addition to clinical, supervisory, and management activities at UCSF, Sarah coordinates monthly continuing education workshops for dementia care navigators and leads monthly implementation meetings for health systems and community-based organizations adapting the Care Ecosystem model for their setting.

Gary Epstein-Lubow, MD, is a Distinguished Medical Scholar at the Education Development Center (EDC), a geriatric psychiatrist, and a national leader in dementia-related research and policy. Dr. Epstein-Lubow's work focuses on enriching the lives of people living with dementia and their family members by improving the quality of dementia care and expanding access to care through workforce development and health care system transformation. His work promotes the voices of people living with dementia and caregivers, to advance health equity for groups disproportionately negatively affected by dementia.

Leslie Evertson, DNP, has been serving as a Dementia Care Specialist Nurse Practitioner for the UCLA Alzheimer's and Dementia Care (ADC) program since 2012. She has played an integral role in the program's development and implementation. She is a trainer for the ADC program model of dementia care dissemination effort funded by The John A. Hartford Foundation. She is co-chair of the healthcare system dementia care intervention for a PCORI/NIA-funded pragmatic trial of comparative effectiveness of health systems-based to community-based dementia care. At UCLA Health, Dr. Evertson is active in several healthcare system committees, including the UCLA Health PRIDE network, and serves as the Associate Director of Advanced Practice Providers.

Ian N. Kremer, JD, has worked on federal, state and local dementia policy since 1996. Since 2012, Kremer has served as Executive Director of the LEAD Coalition (Leaders Engaged on Alzheimer's Disease), the uniting voice of over 260 member and allied organizations, along with over 200 university-based researchers. Currently, Kremer serves on the CMS Medicare Evidence Development & Coverage Advisory Committee (MEDCAC), the Public Policy & Aging Report editorial board, steering and advisory committees for the NIA IMPACT Collaboratory, the CDC-funded BOLD Public Health Center of Excellence on Early Detection of Dementia and Public Health Center of Excellence on Dementia Caregiving, the CDC National Healthy Brain Initiative Tribal Project, the NIA-funded Hopkins' Economics of Alzheimer's Disease and Services (HEADS) Center and the WeCareAdvisor Study, the UCLA Dementia Care Study, the Alzheimer's Disease Patient and Caregiver Engagement (AD PACE) initiative, the Dementia Friendly America initiative, and the Davos Alzheimer's Collaborative Champions Cabinet.







Kristin Lees Haggerty, PhD is a public health researcher focusing on the design, testing, and dissemination of innovations to improve health care for older adults. Dr. Lees Haggerty's work focuses on prevention and remediation of elder mistreatment and improving access to comprehensive dementia care. Dr. Lees Haggerty is Project Director for the National Collaboratory to Address Elder Mistreatment and Associate Director of the National Dementia Care Collaborative. Dr. Lees Haggerty was recently awarded an NIH K-01 Career Development grant to investigate elder mistreatment among older adults with cognitive symptoms with mentorship from leading experts in elder abuse and dementia research.

Amy Imes, MSN, is a Gerontological Nurse Practitioner who is a trusted expert in geriatrics, demonstrating a deep understanding of the unique healthcare needs of the aging population. Throughout her career, Amy Imes has played a pivotal role in building care models and developing teams that yield superior outcomes. She is passionate about programs that provide creative solutions to ongoing challenges. In addition to her clinical work, Amy Imes is actively involved in the Gerontological Association of Advanced Practice Nurses Association. She is a member of the team at the Integrated Memory Care clinic at Emory Healthcare, which is a nurse practitioner led primary care practice for patients living with dementia.

Keith Kearney, MSW, is Director of Information Management at Benjamin Rose. He manages large IT related projects across the organization, including software development projects, analytics, and IT security policy. He has over a decade of experience working on the BRI Care ConsultationTM program in various roles. His experience ranges from training BRI Care Consultation Care Navigators to the development and management of BRI Care Consultation's existing software application, the Care Consultation Information System (CCIS).

Kaleigh Ligus, PhD, is a social science research analyst at the Center for Medicare and Medicaid Innovation. Her work includes developing, implementing, and evaluating new CMS patient care models aimed at improving Medicare beneficiaries' health care experiences and health outcomes. Kaleigh currently works on the Guiding an Improved Dementia Experience Model as care delivery, health equity and learning system lead. She has been dedicated to serving older adults living with chronic disease since 2015 after working on the evaluation of the Money Follows the Person program in Connecticut. She earned her doctoral degree in human development and family sciences, with a specialization in adulthood, aging and gerontology, from UConn in 2023. During graduate school, she served as the Greg O'Neill Policy Intern for the Gerontological Society of America and as a Health Policy Fellow at AcademyHealth.

Morgan Minyo, PhD, is a Research Scientist at Benjamin Rose Institute on Aging. Her research focuses on meeting the needs of older adults living with chronic health conditions, including people living with dementia, and their family or friend caregivers by developing and evaluating evidence-based programs that promote engagement with supportive services and navigating care across healthcare and community service organizations. She is a key member of project teams that are working to advance dissemination and successful implementation of evidence-based programs.







Olivia Nirmalasari, MD, is an Assistant Professor of Clinical Medicine at Indiana School of Medicine. As a geriatric clinician and dementia specialist at the Eskenazi Senior Care Clinic and Healthy Aging Brain Center, she is dedicated to improving the quality of life for frail elderly individuals, including those affected by dementia and other cognitive disorders. Eskenazi Hospital is actively involved in the GUIDE project, utilizing the ABC model to increase access to high-quality care by directly addressing the needs of unpaid caregivers of those living with Alzheimer's disease and related dementias. Dr. Nirmalasari has extensive experience in patient care, dedicating her career to enhancing the lives of her patients. In addition to her clinical practice, she is actively involved in the education and training of the next generation of healthcare professionals, mentoring medical students, residents, and fellows.

James Noble, MD, is an Associate Professor of Neurology in the Taub Institute for Research on Alzheimer's Disease and the Aging Brain at Columbia University Irving Medical Center. His clinical, research, outreach, advocacy, and education efforts are focused on modifiable risk factors of cognitive aging and improving awareness of neurological disorders. Aside from his role in the Columbia GUIDE program, he is the clinical core leader of the Alzheimer's Disease Research Center and directs several large programs funded by the National Institute of Aging. He is co-editor of the 14th edition of standard text Merritt's Neurology and is the author of the caregiver handbook "Navigating Life with Dementia" (Oxford University Press/American Academy of Neurology 2022). In 2010 he co-founded Arts & Minds, a non-profit organization which provides art-centered museum based programs to persons with dementia and their care partners.

Miriam Owens was diagnosed with Parkinsonism and Lewy Body Dementia in 2022, while in her mid 50s. She lives in Virginia with her husband of 35 years. Miriam is mother to three adult children and has three precious grandchildren and a sweet dog named Sasha. Teaching and nurturing young children has been her passion, and she has written and self-published books, played piano for and directed church choirs. Her diagnosis required her to change her focus to advocacy. Her primary goal is to erase the stigma of dementia and change the narrative surrounding this complex diagnosis. She believes that there is so much more life to be lived between diagnosis and the late stages of dementia and she is committed to living well, and participating in research to improve diagnosis, treatment and quality of life, as well as the pursuit of a cure. Miriam says, "I know that there is still a plan for my life and I trust that plan completely! God wastes nothing, and neither will I."

Michelle Palmer, BA, is the Sales and Marketing Associate for Benjamin Rose Institute on Aging. Her primary focus is to generate awareness and extend the reach of evidence-based programs developed by the organization, and to match these programs with appropriate community-based and social service organizations across the country. Over the course of her 30-year marketing communications career, Michelle has helped manufacturing, technology and non-profit organizations establish a lasting presence in new







markets through strong content creation, developing strategic marketing campaigns and initiating business alliances.

Nikhil Patel is the founder & CEO of Craniometrix, a care navigation software platform purpose-built for dementia and the GUIDE program. GUIDE participants are faced with 2 challenges: 1) what care model to use and 2) how to deliver that care easily and efficiently. Craniometrix collaborates with the Johns Hopkins MIND at Home team, combining their evidence-based model with software to help GUIDE participants across the country easily and efficiently deliver services. The Craniometrix platform includes compliance tools, AI assistants, and more to make GUIDE easy and cost effective for participants to scale. Using the platform, GUIDE participants are over 50% more efficient than without. Craniometrix is based in NYC and backed by over \$6,000,000 in venture capital.

Kate Possin, PhD, is a neuropsychologist whose research focuses on improving the detection, diagnosis and care for people with neurodegenerative disease. She currently holds the John Douglas French Alzheimer's Foundation Endowed Professorship and is a professor in residence in the Department of Neurology at UCSF. She is the project lead of <u>TabCAT</u>, a software platform for tablet-based cognitive testing frequently used in research studies and clinical services. She is also the principal investigator of the <u>Care Ecosystem</u>, a telephone-based supportive care program for persons with dementia and their caregivers that helped inform the GUIDE payment model.

David B. Reuben, MD, is Archstone Professor at the David Geffen School of Medicine at UCLA and Director of the UCLA Alzheimer's and Dementia Care (ADC) Program and the UCLA Medicare & Medicaid Innovation (CMMI) Guiding an Improved Dementia Experience (GUIDE) program. Dr. Reuben is a past President of the American Geriatrics Society. He served for 8 years on the American Board of Internal Medicine's Board of Directors, including as Chair. Dr. Reuben served as Chief of the UCLA Division of Geriatrics for 31 years. He is a member of the National Advisory Council on Aging for the National Institute on Aging. In 2012, Dr. Reuben received one of the first CMMI Innovations Challenge awards to develop a model program to provide comprehensive, coordinated care for patients with dementia. In 2018, he was awarded a multi-site PCORI- and NIA-funded pragmatic trial (D-CARE) to compare the effectiveness of health system-based versus community-based dementia care versus usual care. Dr. Reuben is also the Principal Investigator of a grant from the John A. Hartford Foundation to disseminate the UCLA ADC program.

Tonya Saffer, MPH, is the Director of the Division of Healthcare Payment Models within the Patient Care Models Group at the at the Centers for Medicare & Medicaid Services'(CMS) Innovation Center. She leads a team of researchers and technical experts working on health care delivery and payment innovations to help people living with serious illnesses remain independent and, in their homes, and communities. Ms. Saffer is a mission-driven leader that has spent her career leveraging skills in policy, research, reimbursement, and economics to improve health and healthcare access for underserved populations and people living with







chronic illness. Prior to joining the CMS Innovation Center in October of 2022, Ms. Saffer was the Vice President of Government Affairs and Market Access for Outset Medical. There she successfully architected and executed a strategy to secure dedicated reimbursement to bring innovations in home dialysis technology to people with kidney failure.

Quincy Samus, PhD, is an associate professor in the Department of Psychiatry and Behavioral Sciences and the founding director of the Memory and Aging Services Innovation Center in the Department of Psychiatry at Johns Hopkins University School of Medicine. She is an applied gerontologist trained in health services research and epidemiology. Dr. Samus has led several large federally funded projects to improve dementia care quality and health care equity through translation of practical evidence-based, and cost-efficient practices to meet the needs of patients, families, providers, and health systems. She is a member of national and international dementia care advisory committees and currently serves as chairperson of the State of Maryland's Virginia I. Jones ADRD Council. The overarching objective of her work is to improve care quality and outcomes through translation of evidence-based practices to real-world settings.

Abiodun Salako, MBBS, PhD, MPH, is a health insurance specialist at the Center for Medicare and Medicaid Innovation (CMMI). Since joining CMMI in 2019, Abiodun has worked as a learning system lead for a number of the Center's models, including the Guiding an Improved Dementia Experience Model. His work includes designing and implementing learning systems that support model participants as they strive to achieve the model's goals. After graduating from medical school in 2009, Abiodun's work has focused on initiatives to improve access to and quality of care for underserved and vulnerable populations. He earned a master's in public health from Harvard University in 2013 and a doctorate in health policy from the University of Iowa in 2019

Rani E. Snyder, MPA, is Vice President, Program at The John A. Hartford Foundation. Ms. Snyder has over 25 years of experience working with preeminent health care institutions across the nation improving the care of older adults, identifying and guiding health care programs that have set the standard for medical best practices, increasing medical education opportunities, and maximizing resources to improve health care broadly. She brings that experience to The John A. Hartford Foundation where she coordinates initiatives that foster collaboration among academic institutions, hospitals and health care providers to build Age-Friendly Health Systems, support family caregivers, and improve serious illness and end-of-life care. She is a board member and past board chair for Grantmakers in Aging, a membership organization comprised of philanthropies with a common dedication to improving the experience of aging, a board member for the American Society on Aging.

Rebecca Jackson Stoeckle is EDC's Senior Vice President and director of Private Sector Partnerships, leading a body of work at the intersection of intervention design and scalable systems change. Balancing innovation and pragmatism, this globally focused work ranges from addressing elder abuse in rural and urban settings to







redressing the COVID-19 disruption of education systems through virtual first job opportunities for at-risk youth to expanding access to evidence-based psychotherapies through direct-to-consumer digital applications. Rebecca's projects have received national recognition and awards for excellence in innovation and sustainable systems change.

Lauranne Scharf, MSHS, LSW, is a Care Consultant and Master Trainer for BRI Care ConsultationTM at Benjamin Rose. She has more than 19 years' experience working with older adults and in the field of aging. Prior to joining Benjamin Rose, she was the Support Services Manager at the Alzheimer's Association-Cleveland Area Chapter delivering caregiver support groups, providing programming for individuals with Early Stages dementia and Late-Stage programs for caregivers. Through her work as a resident's rights advocate and long-term care ombudsman, she has helped to develop and implement training to nursing home staff on creating and delivering person-centered care.

Franklin Shen, MBA, is the Vice President of Clinical Operations at Tembo Health, a digital healthcare company on a mission to make managing dementia care simple. At Tembo Health, Franklin oversees the company's care delivery to seniors as well as manages its participation in the Medicare's GUIDE program. With over 20 years of experience in healthcare, he has worked to improve outcomes, engagement, scale, and leadership in the space.

Lauren Sullivan started out working as a home health aide while in school to become a certified occupational therapy assistant (COTA). In both of those roles, she worked with people that have had various forms of dementia and dementia related illnesses. She worked on a COVID unit during lockdown as both a certified nursing assistant (CNA) and COTA. Laruen has done travel therapy throughout Indiana as well as working in a long-term care/assisted living/rehab facility. Her current role is as a Care Coordinator Assistant (CCA) in the Healthy Aging Brain Center where she also performs neuropsychological testing to assist in diagnosing patients with memory problems as a psychometrist. Her role is to help monitor, provide support and coaching to patients and their families. Lauren is a Care Coach for the GUIDE program at Eskenazi.

Joan Weiss, PhD, is an adult and gerontological nurse practitioner who serves as the Acting Director in the Division of Medicine and Dentistry (DMD) at the Health Resources and Services Administration (HRSA). She oversees workforce development programs in geriatrics, primary care, graduate medical education, mental and behavioral health, health, preventive medicine/public health, and oral health. She is the subject matter expert for the Federal Advisory Committee on Interdisciplinary Community-Based Linkages. She is the HRSA representative on the U.S. Department of Health and Human Services' (HHS) Advisory Council on Alzheimer's Disease Research, Care, and Services; the Family Caregiving Advisory Council; and the Supporting Grandparents Raising Grandchildren Advisory Council. She also serves on HHS interagency workgroups on palliative care, elder justice, and caregiving. She has held many leadership positions at HRSA including Director of the Division of Public Health and Interdisciplinary Education and Acting Director of the Division of Nursing.







She is a recipient of the 2015 Secretary's Meritorious Group Award for taking important steps to find a cure and improve care for people with dementia and the 2022 HRSA Lifetime Achievement Award.

Lisa Weitzman, MMSA, is the Director of Strategic Partnerships at Benjamin Rose. In this role, she seeks to enhance Benjamin Rose's effectiveness in the community by aligning with the business community, health systems, and other community-based organizations to drive Benjamin Rose's mission-driven work to support older adults and the family and friends who care for and about them. She also oversees the delivery of WeCare...Because You Do, Benjamin Rose's own delivery of BRI Care ConsultationTM.





