

**Decadal Survey of Behavioral and Social Science Research on Alzheimer's
Disease and Alzheimer's Disease-Related Dementias**

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Former Member, National Advisory Council for Alzheimer's Research, Care and Services, Living with Alzheimer's disease

JR Pagan

Member, Dementia Action Alliance
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Ed Patterson

Member, Alzheimer's Association Early-Stage Advisory Group, Living with Alzheimer's Disease

Brian Van Buren

Board Member, Western Carolina Chapter of the Alzheimer's Association and Advisory Council Member for the Dementia Action Alliance, Living with Alzheimer's Disease

Caregivers of Individuals Living with AD/ADRD

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Committee Biographies

Tia Powell - (Chair)

Tia Powell is director of the Montefiore Einstein Center for Bioethics and of the Einstein Cardozo Master of Science in Bioethics program. She is professor of epidemiology, Division of Bioethics, and Psychiatry. She focuses on bioethics issues related to public policy, dementia, consultation, end of life care, LGBT people, and public health disasters. She served four years as executive director of the New York State Task Force on Life and the Law, which functions as New York State's bioethics commission. She has worked with the National Academy of Science, Engineering, and Medicine on many projects related to public health and ethics, and most recently served on the 2017 report on community approaches to address health inequities. She received her M.D. from Yale Medical School.

Karen S. Cook - (Vice Chair)

Karen S. Cook (NAS) is the Ray Lyman Wilbur professor of sociology; director of the Institute for Research in the Social Sciences (IRiSS); and vice-provost for Faculty Development and Diversity at Stanford. She conducts research on social interaction, social networks, social exchange, and trust. In 1996, she was elected to the American Academy of Arts and Sciences and in 2007 to the National Academy of Sciences. In 2004 she received the ASA Social Psychology Section Cooley Mead Award for Career Contributions to Social Psychology. She received her Ph.D. in sociology from Stanford University.

Margarita Alegria

Margarita Alegria (NAM) is the chief of the Disparities Research Unit at Massachusetts General Hospital and a professor in the Departments of Medicine and Psychiatry at Harvard Medical School. Her research focuses on the improvement of health care services delivery for diverse racial and ethnic populations, conceptual and methodological issues with multicultural populations, and ways to bring the community's perspective into the design and implementation of health services. She is currently the principal investigator (PI) of three National Institutes of Health (NIH)-funded research studies: Building Community Capacity for Disability Prevention for Minority Elders; Mechanisms Underlying Racial/ Ethnic Disparities in Mental Disorders; and The Impact of Medicaid Plans on Access to and Quality of Substance Use Disorder (SUD) Treatment. In October 2011, she was elected as a member of the National Academy of Medicine in acknowledgement of her scientific contributions to her field. She has also been a recipient of notable awards, most recently she was the recipient of the 2018 Jonathan Mann Award by the New Mexico Public Health Association in recognition of her lifetime commitment to public health and social justice issues. She obtained her B.A. in Psychology from Georgetown University in 1978 and her Ph.D. from Temple University in 1989.

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Deborah Blacker

Deborah Blacker is professor of psychiatry at Harvard Medical School and deputy chair and professor in the Department of Epidemiology at the Harvard T.H. Chan School of Public Health. She is a geriatric psychiatrist and epidemiologist based at Massachusetts General Hospital, where she directs the Gerontology Research Unit and serves as associate chief for Research in the Department of Psychiatry. Her work focuses on the epidemiology, genetics, assessment, and early recognition of Alzheimer's disease. She serves as the leader of the Research Education Component and co-leader of the Clinical Core for the Massachusetts Alzheimer's Disease Research Center, and leader of the Analytic Core for the Harvard Aging Brain Study investigating earliest brain changes in Alzheimer's disease. She is involved in multiple local and national studies regarding Alzheimer's disease genetics and epidemiology and leads the AlzRisk project to develop a curated online catalog of Alzheimer risk factor studies. She is also actively involved in teaching and methodologic research at HSPH, where she co-directs a training program in psychiatric genetics and translational research and teaches a course on assessment methods in psychiatric research. She served on the DSM-5 Neurocognitive Disorders Workgroup, and the American Psychiatric Association's Workgroup to Revise the Practice Guideline for Dementia. She received her M.D. from Harvard Medical School and her Sc.D. in epidemiology from the Harvard T.H. Chan School of Public Health.

Maria Glymour

Maria Glymour is a professor in the University of California, San Francisco (UCSF) Department of Epidemiology and Biostatistics. She currently serves as the director for the UCSF Ph.D. program in Epidemiology and Translational Science at the University of San Francisco. She co-leads the UCSF NIH-sponsored training grant on Aging and Chronic Disease, and the Methods in Longitudinal Research on Dementia (MELODEM) initiative to improve research methods related to cognitive aging, Alzheimer's, and dementia. Her research focuses on how social factors experienced across the life course, from infancy to adulthood, influence cognitive function, Alzheimer's disease and Related Disorders (ADRD), stroke, and other health outcomes in late life. She is especially interested in how exposures amenable to policy interventions shape health. Another line of her work focuses on strengthening quantitative research methods for research on cognitive aging and ADRD. Specific topics have included the geographic patterning of stroke and dementia; the socioeconomic inequalities in healthy aging; the causal effects of education on later life health; the influence of selection/survival bias in models of cognitive aging; lifecourse timing of dementia risk factors; and longitudinal modeling of cognitive change and dementia. Prior to joining UCSF, she was an Assistant Professor at the Harvard School of Public Health. She completed her Sc.D. at the Harvard School of Public Health and post doctoral training at Columbia University.

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Roe Gutman

Roe Gutman is an associate professor of biostatistics at Brown University. His areas of research interest are Bayesian data analysis, missing data, file linkage, causal inference, matching and bioinformatics. He has been involved in many comparative effectiveness studies where he contributed both in terms of the statistical theory and its implementation. He brings vast experience in analyzing many types of secondary datasets from various sources (e.g. Medicare claims data, registries, VA health data), as well as data collected through large pragmatic cluster randomized trials. His work on file linkage addresses problems with combining administrative and clinical data having common elements in which privacy regulations limit access to unique identifiers. He uses missing data techniques to assess uncertainty in the link probabilities and thus develops statistically valid procedures. His work in causal inference seeks to obtain valid comparisons of non-randomized interventions that appropriately adjust for differences in baseline covariates by applying advanced regression modeling techniques to multiply impute the missing potential outcomes. Recent examples of research projects he is involved in include: 1) Combining Rasch modeling with multiple imputations to create a cross-walk for assessments of patients' functional status across the continuum of care (acute, post-acute, and community care settings); 2) Linking HIV+ prisoner records to Ryan White data to assess the adequacy of linkage to care upon re-entry to the community; 3) Assessing the impact of home-delivered meals on fee-for-service Medicare beneficiaries' healthcare utilization and costs by linking Meals on Wheels sites' information to Medicare fee for service files; 4) Participating in the design and analysis of a pragmatic trial that examines the effect of video decision support tools to improved advance care planning; 5) Estimating the effects of different antihyperglycemic drug regimens (mono- or poly-therapy) on the occurrence of myocardial infarction, stroke, and hospitalization for heart failure for diabetes mellitus patients using the CPRD dataset. He received his Ph.D. in statistics from Harvard University.

Mark D. Hayward

Mark Hayward is a professor of sociology, Centennial Commission professor in the Liberal Arts, a faculty research associate of the Population Research Center, and director of the Population Health Initiative at the University of Texas at Austin. He also serves as the training director of the Population Research Center. Recently, Hayward began a collaborative NIA-supported project with Eileen Crimmins, examining trends in the dementia experience of the U.S. older population. At its core, this study is designed to inform our understanding of how education—a crucial Alzheimer's disease risk factor— influences the cognitive health of older Americans. He has served on the National Academies of Sciences, Engineering and Medicine's Committee on Population, was chair of the Future Directions for the Demography of Aging: A Workshop, and was a member of the Committee on Accounting for Socioeconomic Status in Medicare Payment Programs. He received his Ph.D. in sociology from Indiana University.

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Ruth Katz

Ruth Katz is senior vice president for Public Policy at LeadingAge, the Nation's largest association representing not for profit providers of aging services. Ruth joined LeadingAge in January 2018 after a 27-year career in the Office of the Secretary, U.S. Department of Health and Human Services. For the last 20 of those years, she served as the senior career official, the associate deputy assistant secretary for Disability, Aging, and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation (ASPE). Ruth is a trusted leader, coalition builder, research translator, and policy influencer. She is known for leading teams that work on policy analysis and policy research – and the nexus between the two. At ASPE Ruth led the founding and operation of the National Alzheimer's Project Act Advisory Council and the creation of the first national plan and updates that followed. She led the convening of the ASPE/National Institutes of Health (NIH) Research Summit on social science research on Alzheimer's disease and related dementias. She was the staff leader for the United States Health and Human Services Department (HHS) early implementation work on the Community Living Assistance Services and Supports Act (CLASS) program (the Affordable Care Act's Long Term Care title) and led the drafting of the report to repeal CLASS. She oversaw numerous policy research projects on aging, disability, long-term care, and mental health topics and served on Secretarial work groups, including on the response to the opioid crisis. She received her M.Ed. from The George Washington University.

Spero M. Manson

Spero M. Manson (NAM) (Pembina Chippewa) is a distinguished professor of Public Health and Psychiatry, occupies the Colorado Trust Chair in American Indian Health, and directs the Centers for American Indian and Alaska Native Health in the Colorado School of Public Health at the University of Colorado Denver's Anschutz Medical Campus. His programs include 10 national centers, which pursue research, program development, training, and collaboration with 250 Native communities, spanning rural, reservation, urban, and village settings across the country. He has acquired \$250 million in sponsored research to support this work and published more than 250 articles on the assessment, epidemiology, treatment, and prevention of physical, alcohol, drug, as well as mental health problems over the developmental life span of Native people. He was elected to the National Academy of Medicine in 2002 and is widely acknowledged as one of the nation's leading authorities in regard to Indian and Native health. He received his Ph.D. in anthropology at the University of Minnesota.

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Terrie E. Moffitt

Terrie E. Moffitt (NAM) is the Nannerl O. Keohane University professor of psychology and neuroscience at Duke University and professor of social development at King's College London. She studies how genetic and environmental risks together shape the developmental course of problem behaviors. Her initial interest was in antisocial, violent, and criminal behavior, but now also mental health and substance abuse. Currently, she is studying how mental health and brain function affect the body's physical health and aging. She is working on testing whether chronic psychiatric disorders and lifelong poor cognitive abilities accelerate the pace of aging. She co-directs the Dunedin Longitudinal Study, which has followed 1000 people born in 1972 in New Zealand from birth to age 45. She also co-directs the Environmental-Risk Longitudinal Twin Study, which has followed 1100 British families with twins born in 1994-1995 from birth to age 24. She is also a trustee of the Nuffield Foundation, a fellow of the Academy of Medical Sciences, the American Society of Criminology, the British Academy, the American Psychopathological Association, Academia Europaea, the American Academy of Political and Social Science, the Association for Psychological Science, and King's College London. She has served on investigative panels for institutions such as the Nuffield Council on Bioethics (ethics of behavioral genetic research) and the National Academy of Sciences (research into firearms and violence). She received her Ph.D. in clinical psychology at the University of Southern California.

Vincent Mor

Vincent Mor (NAM) is the Florence Price Grant professor of community health in the Brown University School of Public Health and a research health scientist at the Providence Veterans Affairs Medical Center. He was on the faculty of the Department of Community Health in the Brown Medical School since 1981 until it became the Department of Health Services, Policy, and Practice in the School of Public Health. He was tenured in 1987 and was promoted to professor in 1990. He was one of the founders of the Department's graduate program in 1986 and directed the Center for Gerontology and Health Care Research for 10 years. He served as chair of the Department of Community Health from 1996 until 2010. While chair, he instituted an expansion of the Department's graduate programs, growing the doctoral programs in epidemiology and biostatistics and then adding a Ph.D. program in health services research. Has been continuously funded by NIH since 1984, held a MERIT award from NIA, a Robert Wood Johnson Health Policy Investigator and awarded the Distinguished Investigator award from Academyhealth. He currently directs an NIA funded Program Project on Long Term Care services and supports in America. He received his Ph.D. at the Florence Heller School for Advanced Studies in social welfare, Brandies University.

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David B. Reuben

David Reuben is director, Multicampus Program in Geriatrics Medicine and Gerontology and chief, Division of Geriatrics at the University of California, Los Angeles (UCLA) Center for Health Sciences. He is the Archstone Foundation chair and professor at the David Geffen School of Medicine at UCLA and Director of the UCLA Alzheimer's and Dementia Care program. He is a past president of the American Geriatrics Society and former board chair, American Board of Internal Medicine. In 2012, he received one of the first CMMI Innovations Challenge awards to develop a model program to provide comprehensive, coordinated care for patients with Alzheimer's Disease and other dementias. In 2014, he was one of three principal investigators to be awarded a multicenter clinical trial (STRIDE) by the Patient-Centered Outcomes Research Institute (PCORI) and the National Institute on Aging (NIA) to reduce serious falls-related injuries; it is the largest grant that PCORI has awarded. In 2018, he was awarded a multi-site PCORI- and NIA-funded pragmatic trial to compare the effectiveness of health system-based dementia care versus community-based dementia care versus usual care. He continues to provide primary care for frail older persons, including making house calls. He received his M.D. from the Emory University School of Medicine.

Roland Thorpe

Roland J. Thorpe, Jr. is an associate professor in the Department of Health, Behavior and Society (HBS), founding director of the Program on Research for Men's Health in the Hopkins Center for Health Disparities Solutions (HCHDS), deputy director of the HCHDS, and director of the Johns Hopkins Alzheimer's Disease Research Center for Minority Aging. He holds joint appointments in the division of gerontology and geriatric medicine and in neurology at the Johns Hopkins University School of Medicine and in the undergraduate program in public health in the Krieger School of Arts & Sciences. His research focuses on race-, place- and SES-related disparities across the life course in functional and health status of community-dwelling adults with a focus on African American men. Most of his work has been funded by NIA and NIMHD. He has published in various outlets including Journal of Gerontology Medical Sciences, Social Science and Medicine, American Journal of Public Health, and Biodemography and Social Biology. He is a member of the National Committee on Vital and Health Statistics and recently completed a 4-year term on the Advisory Committee on Minority Health at the U.S. Department of Health and Human Services.

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Rachel M. Werner

Rachel Werner (NAM) is the Eilers professor of Medicine and Health Care Management at the Perelman School of Medicine and the Wharton School, both at the University of Pennsylvania. She is also executive director of the Leonard Davis Institute of Health Economics, also at Penn. She is a practicing general internist and a Ph.D.-trained health economist. She divides her time between research on incentives to improve quality of care and her primary care practice at the Philadelphia Veterans Health Administration. Her research has been published in high-impact peer-reviewed journals, including JAMA, Health Services Research, and Health Affairs. Beyond publication, she has influenced policy as a member of the National Quality Forum's Expert Panel on Risk Adjustment and Socioeconomic Status and an advisor to the federal government on quality measurement and quality improvement incentives. In a particularly policy-relevant study, she found that a 5-star rating system has a much greater effect on consumer choice of a nursing home than more complicated measures of quality. She is a core investigator with the Veterans Health Administration HSR&D Center for Health Equity Research and Promotion (CHERP) and also directs one of four national centers to evaluate the effectiveness of the Veterans Health Administration's medical home. She received her M.D. and her Ph.D. in health economics from the University of Pennsylvania.

Kristine Yaffe

Kristine Yaffe is a professor of psychiatry, neurology and epidemiology, the Scola Endowed chair and vice chair in psychiatry, and the director of the Center for Population Brain Health at the University of California, San Francisco (UCSF). She is an internationally recognized expert in the field of cognitive aging and dementia. As the principal investigator of multiple grants from the NIH, DoD, and several foundations, she is particularly interested in identifying novel risk factors for cognitive impairment that may lead to strategies to prevent cognitive decline. She has published over 500 peer-reviewed articles (H-index=130) in numerous prestigious journals including the Lancet, BMJ, JAMA, and NEJM. She served as the co-chair of the Institute of Medicine's Committee on Cognitive Aging which released a report in 2015 entitled, "Cognitive Aging: Progress in Understanding and Opportunities for Action". She is currently a member of the Beeson Scientific Advisory Board and the Global Council on Brain Health and has received several awards for her distinguished, scholarly work, including the American Association for Geriatric Psychiatry's Distinguished Scientist Award and the American Academy of Neurology's Potamkin Prize for Alzheimer's Research. She is dually trained in neurology and psychiatry and completed postdoctoral training in epidemiology and geriatric psychiatry at UCSF. She received a B.S. in Biology-Psychology from Yale University and her M.D. from the University of Pennsylvania.

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Julie M. Zissimopoulos

Julie M. Zissimopoulos is associate professor in the Sol Price School of Public Policy at the University of Southern California. In addition to her faculty appointment, she serves as vice dean for Academic Affairs at the Price School, and director of Research Training and director of the Initiative on Aging and Cognition at the Schaeffer Center for Health Policy and Economics. She is also co-director of USC's Alzheimer's disease focused, Resource Center for Minority Aging Research, funded by the National Institute on Aging (NIA). Her research applies insights and methods from economics to several health policy areas such as risk and health care costs of Alzheimer's disease, medical expenditures, caregiving and financial support between generations of family members. She is currently leading several NIA funded research projects on: the health of caregivers for persons with dementia; the use of and response to drug therapies for non-Alzheimer's disease conditions that influence risk of Alzheimer's disease; and racial and ethnic disparities in health care treatment for Alzheimer's disease. Her recently published research appears in numerous publications such as the Journal of the American Medical Association Neurology, Journal of Gerontology Social Science, Journal of the American Academy of Arts and Sciences, Journal of Health Economics. She is a frequent speaker on the economics of aging and her research is frequently disseminated through the popular press including media outlets such as the New York Times, Washington Post, Los Angeles Times, CNN, and National Public Radio. She received her B.A. summa cum laude from Boston College, her M.A. from Columbia University, and a Ph.D. in economics from the University of California, Los Angeles.

Advisory Panel Biographies

Individuals Living with AD/ADRD

Cynthia Huling Hummel

Cynthia Huling Hummel of Elmira, NY works tirelessly to represent individuals living with Alzheimer's Disease and related dementias. She recently completed a term of service as a member of the National Advisory Council on Alzheimer's Research, Care, and Services. She has served as a National Early-Stage Advisor for the Alzheimer's Association. She presented at the 2017 and 2019 NIH Alzheimer's Research Summits, and has given many other talks in her role as an advocate. She is also active on a local level. She is co-leading a respite care group called "Faithful Friends," and serving on a local committee that plans social programs for those with ADRD. She is especially interested in Alzheimer's research and enrolled in the ADNI study in 2010. Cynthia received her BS from Rutgers College, her MDiv from New Brunswick Theological Seminary and her DMin from McCormick Seminary. She enrolled at Elmira College in 2011 and will be taking her 37th class this fall. A retired pastor, Cynthia speaks to faith communities about offering dementia-friendly programs and services. An artist and author, she also enjoys singing with the band, "Country Magic."

John-Richard (JR) Pagan

John-Richard Pagan is a disabled veteran with a background in Marriage and Family Therapy. In 2012, John-Richard decided to continue his education by working on a doctorate degree in clinical psychology. Unfortunately, at age 47, with one year into his program, John-Richard began to suffer cognitive challenges which impacted his studies, and even after receiving a diagnosis that included mild cognitive impairment and sudden onset adult attention deficit disorder, he was dismissed from his program and left wondering where these changes would take him.

At this time, VA medical doctors have only been able to definitively diagnosis John-Richard's condition as a progressive neurodegenerative disease with moderate cognitive impairments in processing, language, and attention, thus meeting the requirements for early stage dementia with additional symptoms relating to mobility and autonomic dysfunction. However, John-Richard has not allowed this disease to be what defines him. He continues to advocate for his own health and the health of others who live with dementia and Dementia with Lewy Bodies. He is active in his spiritual and social community, and often describes his immediate family as the most vital part of his ongoing support team.

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Ed Patterson

Ed Patterson was diagnosed with Alzheimer's disease in 2018, at the age of 71.

Ed, who formerly worked in the financial sales industry, states that it was his husband David who first started noticing changes in his cognition. The first warning signs were Ed experiencing difficulty with stressful tasks like making airline reservations, and episodes of repetition. David also noticed that Ed's mood was affected – he seemed to have a short fuse and quick mood swings – and convinced Ed to bring these symptoms up with his doctor. After performing poorly on cognitive tests, Ed was given a PET scan that was inconclusive for Alzheimer's. Ultimately, Ed entered a clinical trial for medication through Bioclinica, which allowed him to access another PET scan and a spinal tap that were positive for amyloid and tau.

After receiving his diagnosis Ed states he "shut down," stayed home and didn't talk much to others about what was going on. Eventually he started looking for information and resources related to Alzheimer's and came across individuals living with the disease giving speeches and talking publicly about their experience. "Their messages woke me up, and got me going," Ed says. He "went public" with his diagnosis on Facebook and became involved with the Florida Gulf Coast chapter in advocacy, fundraising, and programming.

Ed currently lives with David in Clermont, Florida, and works part-time at Disney World.

Brian Van Buren

Brian Van Buren is an Alzheimer's advocate and public speaker, a Board Member of the Western Carolina Chapter of the Alzheimer's Association, and an Advisory Council Member for the Dementia Action Alliance. He was diagnosed in 2015 with early onset Alzheimer's. He was also a caretaker for his mother, who died in January from Alzheimer's. After losing his job as an international flight attendant, Mr. Van Buren reimagined himself as an advocate, giving his voice to Alzheimer's. Being an Afro American man, he felt he needed to give a face to the disease. He was featured in a video for AARP's announcement presenting \$60 million to fund dementia research. He also feels a need to address marginalized populations such as the LGBTQ community.

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Caregivers of Individuals Living with AD/ADRD

Marie Israelite

Marie Israelite serves as the Director of Victim Services at the Human Trafficking Institute. She previously served as the Chief of the Victim Assistance Program at Homeland Security Investigations, where she directed policy efforts, program development, and victim services for all federal crime victims, including survivors of human trafficking and child exploitation. Marie has held several positions within the Department of Homeland Security and the Department of Justice related to human trafficking, sexual assault, and domestic violence prevention and services. Most recently, she served as a Senior Program Manager with ICF, where she facilitated the work of the U.S. Advisory Council on Human Trafficking. Marie is a graduate of Bucknell University and the University of Pennsylvania. She lives in Washington, DC with her husband and two daughters. Her mother Lucy, a retired pediatrician, was diagnosed with Alzheimer's Disease in 2017. Marie shares caregiving responsibilities with her mother's younger sister and her brothers.

Geraldine Woolfolk

Ms. Woolfolk, a retired teacher, has had decades of experience as a caregiver for her father, mother, and then her husband who developed early on-set Alzheimer's Disease (AD). As an Adult Education teacher for almost twenty-five years, she – among her many other assignments – had leadership roles in the development and delivery of programs that were specifically designed for people with Alzheimer's Disease or Related Dementias, as well as for their families. She continues to be active with AD support groups, forums, and conferences. She is a valuable resource for individuals, families, and groups who frequently call upon her for information, referrals, and presentations. Ms. Woolfolk is a longtime advocate on all levels of government for varied causes. As an example, she lobbies legislators and policymakers for increased funding for AD research and caregiver support projects that will enable families to keep their loved ones in the home environment and out of institutional settings for as long as possible. In 2011 Ms. Woolfolk was appointed to the first National Alzheimer's Project Act Advisory Council and served on that groundbreaking body for six years. She has a BA in Music, a Lifetime Secondary Teaching Credential, an MPA, a First Tier School Administrative Credential, and many other certifications and recognitions that herald her leadership, accomplishments, and service. A widow, she has three remarkable children and two awesome grandsons.