



## ARCH RESPITE RESEARCH SUMMIT PRESENTERS

### **Joseph Caldwell, PhD, Senior Scientist and Director, Community Living Policy Center, Lurie Institute for Disability Policy, Brandeis University**

Dr. Caldwell has over 25 years of experience in the fields of aging, disability and family caregiving as a researcher, policy expert, and family member. His research has focused on supports for aging caregivers of adults with developmental disabilities, outcomes of person and family-directed supports, and promising practices in family support across the lifespan and disability populations. Prior to Brandeis, he worked to advance federal long-term services and supports policy at the National Council on Aging, Association of University Centers on Disabilities, and as a Joseph P. Kennedy, Jr. Fellow on the Senate Health, Education, Labor, and Pensions Committee. Dr. Caldwell has served on the boards of the National Alliance for Caregiving and Consortium for Citizens with Disabilities. He currently is an appointed member of the RAISE Family Caregiving Advisory Council.



### **Thomas V. Caprio, MD, MPH, MS, FACP, AGSF, FAAHPM, Professor of Medicine, Psychiatry, Dentistry, Clinical Nursing, and Public Health Sciences, University of Rochester Medical Center, Rochester, New York**

Dr. Caprio serves as the Chief Medical Officer for University of Rochester Home Care and the Medical Director for the hospice program. He serves as director of the Finger Lakes Geriatric Education Center at the University of Rochester and oversees the federally-funded HRSA Geriatric Workforce Enhancement Program which provides education and training related to geriatrics and dementia care for health care professionals and family caregivers. Dr. Caprio is Past-President for the National Association of Geriatric Education Centers and the National Association for Geriatric Education as well as the Past-President of the State Society on Aging of New York. In 2008, Dr. Caprio served as the project director for the Long-term Care Council New York Survey of Caregiver Support Services which implemented a statewide survey in partnership with the New York State Office for the Aging to identify gaps in services and make policy recommendations. Since 2012, he has served as the program evaluator for the federal Administration on Community Living-funded New York State Lifespan Respite Program, which implemented a statewide caregiver network, and develop a coordinated system and database of respite care to meet the needs of individuals and their family caregivers across the age and disability spectrum.



**Joseph E. Gaugler, PhD, Robert L. Kane Endowed Chair in Long-Term Care (LTC) and Aging & Professor, Director, School of Public Health Center on Aging, Division of Health Policy and Management, University of Minnesota**

Joseph Gaugler is the Robert L. Kane Endowed Chair in Long-Term Care & Aging in the School of Public Health Division of Health Policy and Management. His 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 longitudinal and mixed methods.



**Susan Jenkins, PhD, Director, Office of Performance and Evaluation, Center for Policy and Evaluation, Administration for Community Living, U.S. Department of Health and Human Services**

Susan Jenkins is the Director of the Office of Performance and Evaluation for the Administration for Community Living, US Department of Health and Human Services. She has 25 years of program evaluation experience. She is ACL's Evaluation Officer, Chief Data Officer, and Performance Officer and is an officer of the Eastern Evaluation Research Society (EERS). She serves on the Federal Interagency Council for Evaluation Policy (ICEP), a task force the American Evaluation Association to advise the AEA Board on the future of funding in evaluation, and teaches a program evaluation class in the School of Public Administration at American University. In 2018-2019, she was on detail with OMB contributing to guidance and evaluation standards related to the Evidence Act of 2018. Previously, she was an evaluation program specialist with the US Peace Corps overseeing international evaluations. She has worked as government contractor conducting evaluation projects with the Office for Juvenile Justice and Delinquency Prevention, the Bureau of Justice Assistance, the Office of National Drug Control Policy, the Substance Abuse and Mental Health Services Administration and the National Cancer Institute.



**Emma Miller, PhD, Senior Research Fellow, School of Social Work and Social Policy, University of Strathclyde, Glasgow, Scotland**

Emma is a registered Social Worker, with ten years' experience working in area teams. Emma obtained her PhD in Sociology in 2004. Since then she has worked in research, policy and practice on developing and embedding personal outcomes in practice, ensuring that what matters to people who use services and carers is at the centre of decision-making, at individual and collective levels. Emma is a member of the Short Breaks Research & Practice Development Group, with members in Scotland and Wales. The group recently completed a review of evidence for respite and short breaks, hosting a video linked conference in May 2020 between the two countries to further progress the research agenda. Emma is also a member of the Eurocarers Research Working Group, connecting researchers and carer support organizations across many EU countries.



**Susan Peschin, MHS, President and CEO, Alliance for Aging Research, Washington, D.C.**

Susan Peschin, MHS, is president and CEO at the Alliance for Aging Research, the leading national non-profit organization dedicated to accelerating the pace of scientific discoveries and their application to improve the experience of aging and health. Since 2012, Ms. Peschin has been a driving force in the growth and success of the organization. As a thought leader on many aging-related issues, she has led the Alliance in efforts to: boost older adult immunization rates; increase NIH Alzheimer’s disease and aging research funding; raise awareness of geriatric cardiac issues; develop *Talk NERDY to Me (NERDY-Nurturing Engagement in Research and Development with You)*, a PCORI-funded, older patient and family caregiver research engagement network; address costs of healthcare and value frameworks; and reform Medicare treatment access issues. She participates in major industry and policy symposiums around the country each year and has published opinion pieces in news outlets nationwide. Ms. Peschin currently serves on the Boards of Heart Valve Voice U.S. and the King Farm Neighbors Village; and on the National Advisory Council for the National Institute on Aging at the NIH. Ms. Peschin earned a B.A. in Sociology from Brandeis University, and a M.H.S. degree in Health Policy from the Johns Hopkins University Bloomberg School of Public Health.



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**Cordelia Robinson Rosenberg, PhD, RN, Professor Pediatrics and Psychiatry, University of Colorado School of Medicine**

From 1993 through June of 2015, Dr. Robinson Rosenberg was Director of JFK Partners, an interdepartmental program of Pediatrics and Psychiatry at the CU School of Medicine. In this role she was responsible for providing leadership and direction to an interdisciplinary professional staff of over 40 faculty members. She has worked in the field of early intervention for children with developmental disabilities as a clinician, researcher and educator of personnel from multiple disciplines since 1973. She has been the PI on over 40 federally funded demonstration, training or research projects in the field of Developmental Disabilities and Intellectual Disabilities.

Work since 2001 has been focused on Autism Spectrum Disorders. She is Co-Principal Investigator on the CDCP funded Colorado CADDRE and Surveillance projects. She is PI on the Colorado site of the SPARK study. She Co-chairs Colorado CANDO (Colorado Autism and Neurodevelopmental Disorders Options), an ad-hoc committee of the Colorado Developmental Disabilities Council. She also serves as the evaluator for Colorado Inclusive Higher Education Pilot Program. Most recently she has joined Colorado’s Employment First Action Partnership.



**Rani E Snyder, MPA, Vice President, Program, The John A. Hartford Foundation, New York, NY**

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, increased 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 also chair of the board for Grantmakers in Aging, a membership organization comprised of philanthropies with a common dedication to improving the experience of aging, a fellow of the New York Academy of Medicine, and previously served as a Volunteer Long-Term Care Ombudsman for the State of Nevada Aging and Disability Services Division.



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**Sarah A. Sobotka, MD MSCP, Assistant Professor of Pediatrics, Developmental and Behavioral Pediatrics, Associate Program Director of Developmental and Behavioral Pediatrics, Medical Director, Comer Outpatient Developmental and Behavioral Pediatric Programs, University of Chicago**

Dr. Sarah Sobotka is Assistant Professor of Pediatrics in the Section of Developmental and Behavioral Pediatrics, Department of Pediatrics at the University of Chicago. Dr. Sobotka is also Associate Program Director of the Developmental and Behavioral Pediatrics Fellowship Training Program at the University of Chicago and Associate Director of the IL Leadership Education in Neurodevelopmental and Related Disabilities (IL-LEND) program.



Dr. Sobotka’s research utilizes mixed methodology to study patients whose disabilities are a sequelae of medical complexity, particularly after prolonged critical illness. She studies trends and is interested in creating efficient and effective healthcare service models which minimize hospitalizations and provide support for families of children with mechanical ventilation dependency. As a Developmental Pediatrician, she is primarily interested in how to enable children at risk for severe disabilities to reach their developmental potentials. Dr. Sobotka is committed to creating innovative care coordination models to support high risk children and complex care teams.

Dr. Sobotka received her medical degree and a master’s degree in public health sciences for clinical professionals from the University of Chicago. Her clinical training includes pediatric residency at Children’s Memorial Hospital, now Lurie Children’s Hospital/Northwestern Feinberg School of Medicine, and fellowship training in Developmental and Behavioral Pediatrics at the University of Chicago. Dr. Sobotka has received research funding from the National Institutes of Health (NIH): the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD), the Health Resources and Services

Administration (HRSA), as well as several internal awards at the University of Chicago. In 2019, the University of Chicago Department of Pediatrics selected Dr. Sobotka to receive the Early Career Peter Huttenlocher Award for Scholarly Excellence.

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**Sarah Swanson, MPH, Assistant Professor, Community and Family Resource Specialist, Munroe-Meyer Institute, University of Nebraska Medical Center**

Sarah Swanson is an Assistant Professor at the University of Nebraska Medical Center’s Munroe-Meyer Institute, the state’s federally-designated University Center for Excellence in Developmental Disabilities (UCEDD). She has her Master’s in Public Health and has two children with special healthcare needs. Sarah is interested in conducting translational research and engaging people with disabilities and families to shape programming and drive policy changes. She has worked with state leadership to evaluate the impact of respite programs, created a training program for respite providers, and developed programming to educate employers on the needs of working family caregivers and how they can best support these employees. Finally, she manages a program that places Family Navigators (parent leaders who have children with disabilities) in primary care clinics to connect families to early intervention services and help them navigate medical systems, school systems, and community resources in order to improve supports to family caregivers and overall health outcomes. In 2019, she served as a virtual fellow at the Association of University Centers for Disabilities (AUCD) where she partnered with their policy team to create a policy brief on “Best Practices and Innovations in Medicaid Managed Long-Term Services and Supports”- which provided specific examples of states who have created innovative programs to support family caregivers.



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**Rebecca Utz, PhD, Associate Professor, Director of Graduate Studies, Department of Sociology, Director, Health Society & Policy program, Co-Director, Consortium for Families & Health Research, University of Utah**

Rebecca Utz is an Associate Professor in the Department of Sociology at the University of Utah, where she is also a faculty affiliate in Gerontology and Nursing, Director of the “Health, Society & Policy” program (undergrad interdisciplinary major), and Co-Director of the “Consortium for Families & Health Research” (C-FAHR). She is an interdisciplinary life course scholar committed to the study of health and aging, with particular research interests related to how aging families cope with end-of-life transitions such as bereavement, caregiving, and palliative care planning. Currently, she is PI on an R01 project funded by the National Institute on Aging (NIA) to develop and test an online intervention to maximize dementia caregivers’ use of respite time.



**Tiffany Washington, PhD, John A. Hartford Geriatric Social Work Scholar, Associate Professor, University of Georgia School of Social Work**

Dr. Tiffany Washington joined the University of Georgia School of Social Work faculty in 2013 after completing her PhD at the University of North Carolina at Chapel Hill. She publishes in aging, health/minority health, and caregiving. In the area of chronic kidney disease, Dr. Washington's research examines the relationship between psychosocial factors and self-management behaviors. In addition, her work is concerned with factors that facilitate and impede the uptake of health promotion intervention in dialysis facilities. In the area of caregiving, Dr. Washington designed and pilot-tested a caregiver respite program in which student volunteers deliver in-home respite visits to caregivers of persons with dementia. Recently, Dr. Washington was awarded a grant from the Health Foundation for Western & Central New York to examine the relationship of respite dose to psychosocial factors in caregivers. Dr. Washington is the recipient of numerous awards and honors including the Gulf South Summit Outstanding Faculty Contributions to Service- Learning in Higher Education Research Award and the National Institutes of Health Loan Repayment Award for health disparities research.



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**Kim E. Whitmore, PhD, RN, CPN, Assistant Professor, School of Nursing and Master of Public Health Program Faculty, School of Medicine and Public Health, University of Wisconsin - Madison\***

Dr. Kim Whitmore, PhD, RN, CPN has more than 15 years of progressive leadership experience working with communities as a home-care nurse manager, private duty nurse, local Health Officer, Policy Section Chief and State Health Plan Officer for the Wisconsin Division of Public Health, educator and research scientist. Currently, Dr. Whitmore is an Assistant Professor in the School of Nursing at UW-Madison where she helps to cultivate the next generation of nurse leaders who will transform the healthcare system. The overall goal of her research program is to inform the development of a care delivery system that promotes family self-management in families of children with special healthcare needs in order to optimize individual and family outcomes. Kim is also an American representative of the International Short Break Association Committee.



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**Bill Zagorski, C.E.O. of American Senior Care Center, Inc., and Chair and Research Committee Chair, National Adult Day Services Association**

Bill Zagorski is the C.E.O. of American Senior Care Center, Inc. overseeing Centennial Adultcare Centers, three Adult Day Health Care centers, home care, and transportation services, serving more than 100 adults each day throughout middle Tennessee. Bill is a Nashville native, who completed his undergraduate degree at Xavier University, and his graduate degrees in Cancer and Cell Biology, and Molecular Genetics, Biochemistry, and Microbiology at the University of Cincinnati, College of Medicine in Cincinnati Ohio where he split his career in academic research in cancer biology and molecular genetics.



He and his family returned to Nashville in 2011 and have expanded American Senior Care Centers, Inc. which his parents began more than 20 years before. In addition to his role with American Senior Care Centers, Bill is the President of the Tennessee Association of Adult Day Services, the Chair of the Tennessee

Coalition for Better Aging, and Chair of the Research Committee and Chair of the Board for the National Adult Day Services Association.

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**ARCH Staff/Consultants and Summit Facilitators**

Casandra Firman, MS

Susan Janko Summers, PhD

Ray Kirk, PhD

\* Kim Whitmore, PhD, RN - Presenter and Summit Facilitator

Marcia O'Malley - Mindful Media Services

Adam Todd - Zoom Technical Services



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