University of Pittsburgh | National Rehabilitation Research and Training Center on Family Support

Building Bridges: Advancing Family Caregiving Research Across the Lifespan

Second Biennial Conference on Caregiving Research

September 30 – October 1, 2022

Conference Agenda Day One Friday, September 30, 2022	
7:00 AM	Registration and Breakfast
7:55 AM	Welcome to the Conference **Heidi Donovan, PhD, RN, Conference Chair** Co-Director, National RRTC on Family Support Professor of Nursing and Medicine University of Pittsburgh Co-Founder and Director, Family CARE Center at Magee-Womens Hospital University of Pittsburgh Medical Center
8:00 AM	Introduction to the conference through the lens of IOM+6 **Richard Schulz, PhD** Chair, Advisory Board for the National RRTC on Family Support Distinguished Service Professor of Psychiatry, Emeritus Director Emeritus, University Center for Social and Urban Research University of Pittsburgh ***Session Synopsis:*** *It has been 6 years since the landmark Institute of Medicine report on the state of family caregiving in America. The report recommended specific strategies to address the health, economic, and social issues facing family caregivers of older Americans. Dr. Schulz will make some brief comments on significant changes that have occurred in the last 6 years.*
8:15 AM	Session One: Caregiving as a Public Health Priority *Featured Speaker:* **Courtney Van Houtven, PhD** Professor, Department of Population Health Science, Duke University School of Medicine and Duke-Margolis Center for Health Policy Research Scientist, Health Services Research and Development in Primary Care at the Durham Veteran's Administration *Moderator:* **Richard Schulz** ***Session Synopsis:*** *Currently, family caregiving is treated as a private health issue, leading to consequences that remain unaddressed by the public health system. This presentation will define public health to demonstrate that family caregiving is a public health issue. Then, risk factors and consequences of family caregiving that could be addressed by the U.S. public health system will be contrasted with the ways in which they are not addressed by private health systems, employers, and policies.*

Friday, September 30, 2022 (continued)	
9:00 AM	Stretch Break
9:10 AM	Session Two: Understudied Caregiver Populations *Featured Speakers:* **Ann-Marie Rosland, MD, MS** Associate Professor of Internal Medicine, University of Pittsburgh Director, Caring for Complex Chronic Conditions Research Center Core Investigator, VA Pittsburgh Center for Health Equity Research and Promotion Director, High Risk Network and Analytic Core, VA Office of Primary Care **Ranak Trivedi, PhD** Director of Caregiving and Family Systems, Stanford Center for Asian Health Research and Education (CARE) Assistant Professor, University Medical Line, Psychiatry and Behavioral Sciences Stanford University *Moderator:* **Beth Fields, PhD, OTR/L, BCG** Project PI, National RRTC on Family Support, University of Pittsburgh Assistant Professor, Department of Kinesiology University of Wisconsin-Madison ***Session Synopsis:*** *It is critical to include historically understudied and marginalized populations in caregiving research, but researchers are not adequately trained to successfully engage these communities. Research methods and findings from two exemplar caregiver intervention studies will be presented along with lessons learned about barriers and facilitators to successfully engaging individuals from historically understudied or marginalized populations in research, from inception to dissemination.*
10:10 AM	Coffee & Conversation
10:40 AM	Family Perspectives Panel **Amber Thompson, Family Caregiver** Founder and Principal Consultant, Leaders of Change Founder, de-bias
11:10 AM	Session 3: Featured Abstracts – Policy and Understudied Caregivers **Katherine Miller, PhD** – *Comparison of State Policies on Caregiver Support* Postdoctoral Researcher, Medical Ethics and Health Policy, University of Pennsylvania Associate Fellow, Leonard Davis Institute of Health Economics **Michael Reese Wittke, BSW, MPA** –*Recognizing Caregiver Needs: A Policy Framework for Building Caregiver Support Through a Public Health Lens* Vice President for Research & Advocacy, National Alliance for Caregiving **Feylyn Lewis, PhD** – *ME-WE Project: Impact on Mental Health and Well-Being Through Co-Production with European Adolescent Young Carers* Program Manager, Vanderbilt University *Moderator:* **John A. Harris, MD, MSc** Assistant Professor of Obstetrics, Gynecology, and Reproductive Sciences, University of Pittsburgh School of Medicine

Friday, September 30, 2022 (continued)	
12:00 PM	Buffet Lunch & Policy Panel Discussion
12:20 PM	*Keynote Speaker:* **Senator Bob Casey**
12:40 PM	*Featured Panelists:* **Nancy Murray** Senior Vice President, Achieva President, The Arc of Greater Pittsburgh at Achieva **Alan Stevens, PhD** Vernon D. Holleman-Lewis M. Rampy Centennial Chair in Gerontology and Director, Center for Applied Health Research, Baylor Scott & White Health Professor of Medicine and Public Health at the Texas A&M Health Science Center **Michael Reese Wittke, MPA** Vice President, Policy & Advocacy, National Alliance for Caregiving *Moderator:* **A. Everette James, JD, MBA** Director, Health Policy Institute M. Allan Pond Professor, Health Policy and Management Associate Vice Chancellor for Health Policy and Planning, Schools of the Health Sciences University of Pittsburgh **Session Synopsis:** *Senator Casey will present his legislative priorities related to caregiving, the work of the Special Committee on Aging, and the importance of caregiving research to inform policy. Following the presentation, Everette James will facilitate a discussion of the recently released 2022 National Strategy to Support Family Caregivers, as required by the Recognize, Assist, Include, Support and Engage (RAISE) Family Caregivers Act.*
1:30 PM	Session 4: Cross-Cutting Assessment & Intervention *Featured Speaker:* **Erin Kent, PhD** Associate Professor and Chair, Department of Health Policy and Management Gillings School of Global Public Health University of North Carolina *Moderator:* **Allison Applebaum, PhD** Associate Attending Psychologist, Memorial Hospital for Cancer and Allied Diseases Associate Member, Memorial Sloan Kettering Cancer Center Director, Caregivers Clinic, Department of Psychiatry and Behavioral Sciences ***Session Synopsis:*** *Many caregivers are caring for individuals with multiple chronic conditions. Finding commonality in caregiver assessments and interventions across specific diseases is critical for advancing the science of caregiver support. This presentation will synthesize cross-cutting issues in caregiving across serious illness and disability, discuss the general problem with funding siloes in caregiving research, provide examples of research partnerships across serious illness, and emphasize the benefits of viewing caregiving from a life course perspective.*

Friday, September 30, 2022 (continued)	
2:00 PM	Session 5: Value of Cross-Cutting Caregiving Research *Featured Speakers:* **Scott Beach, PhD** Co-Director, National RRTC on Family Support Director, Survey Research, University Center for Social and Urban Research University of Pittsburgh **Esther Friedman, PhD** Research Associate Professor Associate Director, Panel Study of Income Dynamics Survey Research Center, Institute for Social Research, University of Michigan *Moderator:* **Allison Applebaum** ***Session Synopsis:*** *Existing regional and national datasets exist as a resource to advance research on caregiving across the life course, but these resources are not well-utilized. This presentation will describe a variety of public data sources for studying caregiving and disability over the life course and provide in-depth examples of how these datasets have been used to inform caregiving research and policy. Gaps in existing datasets and future directions for research will be discussed.*
2:45 PM	Stretch Break / Hang Friday Posters
3:00 PM	Session 6: Featured Abstracts – Cross-Cutting Analyses **Niying Li, PhD –** *Beyond ADLs and IADLs: Improving Measurement of Caregiving Intensity* Post-Doctoral Fellow, Pharmacotherapy Outcomes Research Center, College of Pharmacy, University of Utah **Tara Klinedinst, PhD, MSOT –** *Understanding Participation Restriction in Mid-life Family Caregivers* Assistant Professor, Department of Rehabilitation Sciences, College of Allied Health, The University of Oklahoma **Kristin Litzelman, PhD –** *Interdependence of depressed mood in caregiver-care recipient dyads: Moderation by health condition and relationship type* Associate Professor, Human Development and Family Studies, Center for Demography of Health and Aging, University of Wisconsin-Madison *Moderator:* **Scott Beach**
3:45 PM	Stretch Break / Hang Friday Posters

Friday, September 30, 2022 (continued)	
4:00 PM	Session 6: Already Toast: Caregiving and Burnout in America *Keynote Speaker:* **Kate Washington, PhD** Author, *Already Toast: Caregiving and Burnout in America* *Moderator:* **Pamela Toto, PhD, OTR/L, BCG, FAOTA, FGSA** Project PI; National RRTC on Family Support Professor of Occupational Therapy Director, Doctor of Clinical Science in Occupational Therapy Program University of Pittsburgh ***Session Synopsis:*** *The demands facing family caregivers and the lack of practical and policy-based supports are not adequately represented in publications targeting the public. Kate Washington combines her academic training and personal experience as a spousal caregiver to highlight the time and labor demands of caregiving and the financial, psychosocial, and health impacts. She also brings recommendations for changes in policy and clinical practice that can better support caregivers, particularly in the context of the continuing pandemic.*
5:00 PM	Day 1 Conference Summary **Scott Beach, Heidi Donovan, and Bambang Parmanto** Co-Directors, National RRTC on Family Support
5:30 PM	Poster Session and Reception Book Signing with Kate Washington
8:00 PM	*End of Day One – Opportunity to hang Saturday a.m. posters*

Conference Agenda Day Two Saturday, October 1, 2022	
7:00 AM	Posters and Breakfast
8:20 AM	Welcome to Day Two **Heidi Donovan** Conference Chair Co-Director, National RRTC on Family Support, University of Pittsburgh
8:30 AM	Session One: Rising Star: The Future of Caregiving Research *Featured Speaker:* **Sheria G. Robinson-Lane, PhD, RN** Assistant Professor, Department of Systems, Populations and Leadership, University of Michigan School of Nursing *Moderator:* **Heidi Donovan** ***Session Synopsis:*** *Significant disparities exist in the social, financial, and health outcomes of family caregivers—particularly family caregivers of persons with dementia. Equitable health outcomes can only occur after examining and responding to these disparities. This presentation will examine culturally-responsive and community engaged care practices that can adequately support families and improve equitable health outcomes for caregiver and the persons they support.*
9:10 AM	Session Two: Technology-Supported Caregiver Interventions *Featured Speakers:* **Sara Czaja, PhD** Director, Center of Aging and Behavioral Medicine Professor of Gerontology Weill Cornell College of Medicine **Bambang Parmanto, PhD** Co-Director, National RRTC on Family Support Professor and Chair, Department of Health Information Management School of Health and Rehabilitation Sciences University of Pittsburgh *Moderator:* **Alan Stevens, PhD** Vernon D. Holleman-Lewis M. Rampy Centennial Chair in Gerontology and Director, Center for Applied Health Research, Baylor Scott & White Health Professor of Medicine and Public Health at the Texas A&M Health Science Center ***Session Synopsis:*** *Technology plays an important role in supporting family caregivers, but gaps remain in policy, research, and system design. Rigorous research with diverse populations in diverse contexts is needed to identify the types of technology applications that best meet caregiver, patient, and provider needs. Presenters will provide an overview of the role of technology in supporting family caregivers and specific examples of technology-based caregiver intervention trials with a focus on mhealth applications. Challenges associated with implementing technology-based interventions and gaps in policy, research, and system design will be discussed.*

Saturday, October 1, 2022 (continued)	
10:10 AM	Posters, Coffee & Conversation
10:40 AM	Family Perspectives Panel **Carolyn Tomko, Family Caregiver** System Administrator, Software Engineering Institute Carnegie Mellon University **Heather Tomko** Outreach Coordinator, National RRTC on Family Support University of Pittsburgh
11:10 AM	Session 3: Featured Abstract: FACE-Rare – A technology supported palliative care intervention for children and families living with ultrarare diseases. **Jessica D. Thompkins, BSN, RN, CPN** Research Nurse Coordinator, Conway Nursing Research Scholar Children's National Hospital *Moderator:* **Grace Campbell, PhD, MSW, CRRN, FARN** Project PI, National RRTC on Family Support, University of Pittsburgh Assistant Professor, Duquesne University School of Nursing Co-Founder, Family CARE Center , UPMC Magee Gynecologic Oncology Fellow, Betty Irene Moore Fellowship for Nurse Leaders and Innovators ***Session Synopsis:*** *The palliative care needs of children living with ultrarare diseases and their carers are not well known. Family prioritized palliative care needs based on the Carer Support Needs Assessment Tool (CSNAT) process will be presented with results from beta testing of the FACE-Rare intervention with 7 families and pilot testing results from the modified FACE-Rare intervention with 30 child/ family dyads.*
11:30 AM	Session 4: Equitable and Inclusive Design of Technologies to Support Caregivers *Featured Speaker:* **Christina Harrington, PhD** Assistant Professor, Human-Computer Interaction Institute Carnegie Mellon University *Moderator:* **Ranak Trivedi, PhD** Director of Caregiving and Family Systems, Stanford Center for Asian Health Research and Education (CARE) Assistant Professor, University Medical Line, Psychiatry and Behavioral Sciences Stanford University ***Session Synopsis:*** *Equitable access to health technologies in the home is lacking and little is known about how to equip communities to address equity in access to health technologies to support caregiving and aging in place. This presentation will discuss inclusivity, how to consider minoritized older adults in the development of health technologies, and ways to incorporate equity/inclusivity in the design of technology systems. Inclusivity in the research practice itself and the ethics of technology system design will also be discussed.*

Saturday, October 1, 2022 (continued)	
12:00 PM **12:20 PM**	Buffet Lunch & Funding Panel Discussion *Featured Panelists:* **Anne Ordway, PhD** Program Specialist, National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR) **Sarah Ruiz, PhD** Senior Program Officer, Patient-Centered Outcomes Research Institute (PCORI) **Ashley Wilder Smith, PhD, MPH** Chief, Outcomes Research Branch, Healthcare Delivery Research Program, National Cancer Institute **Heather M. Snyder, PhD** Vice President, Medical & Scientific Relations, Alzheimer's Association **Rani E. Snyder, MPA** Vice President of Programs, The John A. Hartford Foundation *Moderator:* **Erin Kent** ***Session Synopsis:*** *Program officers from public and private funding agencies will present research priorities and opportunities to support family caregiving research.*
1:30 PM	Session 4: Caregiving Across Transition *Featured Speakers:* **Andrew McCormick, MD, FAAP** Director, Healthy Transitions Center, Down Syndrome Center of Western PA Associate Professor of Pediatrics Paul C. Gaffney Division of Pediatric Hospital Medicine UPMC Children's Hospital of Pittsburgh **Jennifer Lingler, PhD, MA, CRNP, FAAN** Professor and Vice Chair for Research Department of Health and Community Systems, School of Nursing Professor, Center for Bioethics and Health Law University of Pittsburgh *Moderator:* **Justin Yu, MD, MS** Assistant Professor, Department of Pediatrics, School of Medicine University of Pittsburgh Supportive Care Team Member at the Children's Hospital of Pittsburgh of UPMC ***Session Synopsis:*** *<u>Presentation 1:</u> There is no widespread practice for individualized transition planning for adolescents/young adults with developmental disabilities and their family caregivers. This presentation will define the need for transition planning and share a framework for transition planning through the steps of Discovery, Tracking, Preparing, Planning, Transferring and Completing. A Transition Tool Kit will be shared as an exemplar of operationalizing transition planning.*

Saturday, October 1, 2022 (continued)	
	Session 4: Caregiving Across Transition (continued) *<u>Presentation 2:</u> Biomarker testing for Alzheimer's disease is becoming more important, but the impact this has on caregivers and caregivers-to-be is not fully understood. This presentation will provide an overview of biomarker testing for Alzheimer's disease (AD) and its significance as the field transitions from a syndromal to a biological definition of AD. The role of family care partners in patients' decision making around biomarker testing will be discussed with emerging evidence on the impact of AD biomarker testing on family care partners.*
2:30 PM	Stretch Break
2:40 PM	Session 5: The Future of Caregiving Research *Keynote Speaker:* **Joseph Gaugler, PhD** Professor and Robert L. Kane Endowed Chair in Long-Term Care and Aging Director, Center for Health Aging and Innovation Director, BOLD Public Health Center of Excellence on Dementia Caregiving School of Public Health, University of Minnesota *Moderator:* **Ann-Marie Rosland** ***Session Synopsis:*** *Effective dissemination and implementation strategies are needed for evidence-based/ evidence informed programs that support caregivers across diverse contexts. This keynote presentation will summarize the state of the science of caregiving research, particularly for older adults, review gaps in the existing science, and present directions for future research to advance caregiving science.*
3:40 PM	Session 6: Featured Abstracts – Emerging Issues **Jooyoung Kong, MSW, PhD** *Childhood Abuse and Adult Relationships with Perpetrating Parents: Impacts on Depressive Symptoms of Caregivers of Aging Parents* Assistant Professor, Sandra Rosenbaum School of Social Work University of Wisconsin-Madison **Kristin Cloyes, PhD, MN, RN** *Comparing cancer survivors' and their care partners' audio diaries reflecting on stress and social support during the COVID-19 pandemic* Elnora E. Thomson Distinguished Professor, Oregon Health & Science University **Kim Whitmore, PhD, RN, CPN** *Advancing Respite by Building Bridges among Respite Researchers* Assistant Professor, College of Nursing, Marquette University **Kate Perepezko, PhD** *The Role of Caregivers in the Quality of Life of People with Parkinson's Disease: A mixed methods study* Postdoctoral Fellow, National RRTC on Family Support University of Pittsburgh *Moderator:* **Tara Klinedinst**

4:25 PM	Abstract Awards Conference Wrap-Up and Future Planning **Heidi Donovan & Beth Fields** National RRTC on Family Support
4:45 PM	*End of Conference* Thank you for your active engagement in this 2nd biennial conference on caregiving research. We look forward to your feedback on the conference to guide future meetings.