



**CARR Meeting
Agenda
October 23, 2023
3:00 pm – 4:30 pm EST**

Meeting Location: TEAMS

Meeting Attendees:

Joseph Caldwell, PhD Director, Community Living Policy Center Lurie Institute for Disability Policy Brandeis University, Waltham, MA	Lauren J. Parker, PhD Assistant Scientist Department of Health, Behavior and Society, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD	Sarah Swanson, MPH Assistant Professor & Family Support Coordinator UNMC Munroe-Meyer Institute University of Nebraska Medical Center, Omaha, NE
Thomas V. Caprio, MD, MPH, MS Professor of Medicine/Geriatrics, Psychiatry, Dentistry, Clinical Nursing, & Public Health Sciences, University of Rochester Geriatric Assessment Clinic Chief Medical Officer, UR Medicine Home Care & Hospice Rochester, NY	Susan Peschin, MHS President and CEO Alliance for Aging Research Washington, DC	Rebecca L. Utz, PhD Associate Professor, Department of Sociology Director, Health Society & Policy Program Co-Director, Consortium for Families & Health Research University of Utah, Salt Lake City, UT
Joseph E. Gaugler, PhD Robert L. Kane Endowed Chair in Long-Term Care and Aging & Professor Director, Center for Healthy Aging & Innovation Division of Health Policy and Management School of Public Health, University of Minnesota, Minneapolis, MN	Cordelia Robinson Rosenberg, PhD, RN Professor of Pediatrics and Psychiatry Emeritus University of Colorado School of Medicine Aurora, CO	Member and CARR Facilitator Kim Whitmore, PhD, RN, CPN Assistant Professor, College of Nursing Marquette University, Milwaukee, WI
Ken Genewick Program Officer for Caregiving Health Foundation for Western and Central New York Buffalo, NY	Rani E. Snyder Vice President, Program The John A. Hartford Foundation New York, NY	Staff
		Jill Kagan, MPH, Director, ARCH
Tamar Heller, PhD Distinguished Professor, Department Head Director—IDHD, Disability and Human Development College of Applied Health Sciences University of Illinois at Chicago, Chicago, IL	Sarah A. Sobotka, MD MSCP Assistant Professor, Section of Developmental and Behavioral Pediatrics The University of Chicago, Chicago, IL	Susan Summers, PhD, ARCH Consultant
		Casandra Firman, MS. ARCH Consultant
		Lori Stalbaum and Emily Anozie, Administration on Aging, Administration for Community Living



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Context:

Overarching Objective:	The purpose of the Committee for Advancement of Respite Research (CARR) is to advise ARCH on the execution of its respite research initiative and help advance a respite research agenda that supports activities and innovations to develop an evidence base for respite care and related services.
Meeting Facilitators: Jill Kagan and Kim Whitmore	Meeting Recorder: Kim Whitmore

Agenda:

Topic/Description:	Discussion and Follow-Up Needed
Introductions and Review of Agenda	
ARCH Updates (Jill) <ul style="list-style-type: none"> • Update on ARCH Innovative and Exemplary Respite Evaluation Mini-grants • National Lifespan Respite Conference – Call for Presentations • Comments to National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Draft 2024-2028 Long-Range Plan • CARR comments on AHRQ Technical Brief 	
National Strategy to Support Family Caregivers <ul style="list-style-type: none"> • Link to National Strategy: https://acl.gov/CaregiverStrategy • National Strategy ACL Grants Awarded <ul style="list-style-type: none"> • Goal 1: Increase awareness of and outreach to family caregivers (Community Catalyst) 	



<ul style="list-style-type: none"> • Goal 2: Advance partnerships and engagement with family caregivers (Regents of the University of California, San Francisco) • Goal 3: Strengthen services and supports for family caregivers (USAgging) • Goal 4: Ensure financial and workplace security for family caregivers. (Not yet funded – issued new FOA) • Goal 5: Expand data, research, and evidence-based practices to support family caregivers (National Alliance for Caregiving) • Anything else we should do related to the National Strategy? 	
<p>Work Group Updates (Kim)</p> <p>Work Group 1: Define and measure the value of respite</p> <ul style="list-style-type: none"> • The Value of Respite Care White Paper (complete) • Dissemination Opportunities <ul style="list-style-type: none"> • How have you been disseminating information? • Dissemination Materials (Will create for both White Papers) <ul style="list-style-type: none"> • List of conferences • 1-page Flyer • Slide deck • Review Potential Funder List and letter • PCORI update – Meeting with Sarah Ruiz <p>Work Group 2: Recommend common data elements (CDE) for respite-related research</p> <ul style="list-style-type: none"> • Review draft of CDE White Paper • Schedule Work Group meeting • Review National Survey List and letter • National Core Indicators (NCI) connection (Sarah Swanson) 	

<p>Work Group 3: Expand culturally appropriate research with historically underrepresented populations</p> <ul style="list-style-type: none"> • Environmental Scan (complete but ongoing) <i>Resources for Culturally and Linguistically Competent Respite Research</i> https://archrespite.org/library/environmental-scan-resources-for-culturally-and-linguistically-competent-respite-research/ • Update on Ensuring Cultural and Linguistic Competence: A Guide for Respite Researchers: January Listening Session for CARR Members with Georgetown University National Center for Cultural Competence • Public Health Center of Excellence on Dementia Caregiving Update on Resources for Cultural Adaptations of Services and Cultural Adaptation Toolkit • Other Resources? 	
<p>Timeline for CARR Work</p> <ul style="list-style-type: none"> • Work Group Next Steps • Any desire for additional work group meetings/activities? 	
<p>Respite Research Summit</p> <ul style="list-style-type: none"> • Format (consider doing 3 mini-summits for each work group) • Tentative Agenda <ul style="list-style-type: none"> a. Formation of CARR Priorities/National Strategy Alignment a. Panel Presentation on ARCH Innovative and Exemplary Respite Evaluation Findings b. Respite Research Guide on Cultural and Linguistic Competence in Respite Research 	



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<ul style="list-style-type: none"> c. Framework for Measuring the Value of Respite d. Recommendations for Common Data Elements in Respite Research e. Emerging research/evaluation f. Participant input through small group roundtable discussions 	
<p>Items for Future Discussion (ALL)</p> <ul style="list-style-type: none"> • Pragmatic trials • Community-engaged research 	
<p>CARR Member Updates (ALL)</p>	<ul style="list-style-type: none"> • Please send Kim any updates you have (include links or articles, as appropriate). • Feel free to reach out any time with questions or ideas for the CARR/ARCH!
<p>Other Discussion (ALL)</p>	
<p>Wrap-up and Next Steps (Kim)</p>	<ul style="list-style-type: none"> • Kim to send meeting notes and recording

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