



# Committee for Advancement of Respite Research (CARR) Meeting Notes

**March 5, 2024**

**3:00 pm – 4:30 pm EST**

**Meeting Location:** Virtual

Meeting Attendees:			
X	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
	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
	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	X	Cordelia Robinson Rosenberg, PhD, RN Professor of Pediatrics and Psychiatry Emeritus University of Colorado School of Medicine Aurora, CO
X	Ken Genewick Program Officer for Caregiving Health Foundation for Western and Central New York Buffalo, NY	X	Rani E. Snyder Vice President, Program The John A. Hartford Foundation New York, NY
			<b>Staff</b>
			X
			Jill Kagan, MPH, Director, ARCH
			X
			Susan Summers, PhD, ARCH Consultant
X	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
			X
			Casandra Firman, MS. ARCH Consultant
			X
			Lori Stalbaum and Emily Anozie, Administration on Aging, Administration for Community Living
			X
			Katie Arnold, UIC (Guest of Tamar)



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**Context:**

<b>Overarching Objective:</b>	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.	
<b>Meeting Facilitators:</b> Jill Kagan and Kim Whitmore	<b>Meeting Recorder:</b> Kim Whitmore	

**Agenda:**

Topic/Description:	Discussion and Follow-Up Needed
<b>Introductions and Review of Agenda</b>	
<b>ARCH Updates (Jill)</b> <ul style="list-style-type: none"> <li>• <a href="#">National Lifespan Respite Conference</a>. Early registration ends April 15<sup>th</sup></li> <li>• <a href="#">AHRQ Evidence Map on Home and Community-Based Services</a>. Comments requested by March 22</li> </ul>	<ul style="list-style-type: none"> <li>• Early registration for NLRC ends April 15th</li> <li>• Kim to review AHRQ Technical Brief to see if they incorporated any of our recommendations and send updated comments (Due March 22<sup>nd</sup>)</li> <li>• Please share any additional comments to Kim by March 18<sup>th</sup> to include with CARR comments or submit your own comments</li> </ul>
<b>Listening Session</b> <ul style="list-style-type: none"> <li>• Summary of <a href="#">Listening Session</a> with the Georgetown National Center for Cultural Competence to inform development of</li> </ul>	<ul style="list-style-type: none"> <li>• Consider reviewing the recording of the listening session if you were unable to attend</li> </ul>



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<p>Research Guide on Cultural and Linguistic Competence in Respite Research</p> <p><b>Respite Research Summit</b></p> <ul style="list-style-type: none"> <li>• Format (consider doing 3 mini-summits aligned with each work group)</li> <li>• Tentative Dates <b>September 24<sup>th</sup>, 25<sup>th</sup></b>, and 18, 23, 30<sup>th</sup>, 1<sup>st</sup> (1-4pm ET) – 18<sup>th</sup> is not good for a few people</li> <li>• Tentative Summit Agenda             <ol style="list-style-type: none"> <li>a. Formation of CARR Priorities/National Strategy Alignment</li> <li>a. Panel Presentation on ARCH Innovative and Exemplary Respite Evaluation Findings (4 “research ready” programs involved who are aligning with CDEs; doing service mapping; including fidelity measures, measuring caregiver wellness outcomes; client satisfaction – trust and communication are coming up as important)</li> <li>b. Respite Research Guide on Cultural and Linguistic Competence in Respite Research</li> <li>c. Framework for Measuring the Value of Respite</li> <li>d. Recommendations for Common Data Elements in Respite Research</li> <li>e. Emerging research/evaluation</li> <li>f. Participant input through small group roundtable discussions</li> </ol> </li> </ul>	<ul style="list-style-type: none"> <li>• If you have ideas for the respite research summit, possible presenters, or want to present your work, please let Jill and Kim know.</li> <li>• May need CARR Members to help facilitate round table discussions</li> </ul>
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<p>CARR Ideas</p> <ul style="list-style-type: none"> <li>• Update on National Strategy Goal 5 Activity</li> <li>• Research at different ages and stages</li> <li>• Highlight Culturally Responsive Research</li> <li>• BREAK Exchange connection</li> </ul>	
<p><b>Update on Common Data Elements Paper (Kim)</b></p>	<ul style="list-style-type: none"> <li>• Feedback by March 15th</li> </ul>
<p><b>Update on Ongoing Work</b></p> <ul style="list-style-type: none"> <li>• Funding Letter</li> <li>• National Survey Letter</li> <li>• PCORI Update</li> </ul>	
<p><b>Items for Future Discussion (ALL)</b></p> <ul style="list-style-type: none"> <li>• Pragmatic trials</li> <li>• Community-engaged research</li> </ul> <p>Note:</p> <ul style="list-style-type: none"> <li>• This is year 4 or 5 for Federal Grant for CARR</li> <li>• Will have 1 more CARR meeting in June, Summit, and Report from Summit</li> </ul>	<ul style="list-style-type: none"> <li>• If you have any other ideas please send them to Kim</li> </ul>



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<p><b>CARR Member Updates (ALL)</b></p>	<ul style="list-style-type: none"> <li>• Please send Kim any updates you have (include links or articles, as appropriate).</li> <li>• Feel free to reach out any time with questions or ideas for the CARR/ARCH</li> <li>• Sarah Swanson working as a consultant on Grassroots Advocacy Initiative</li> <li>• Tamar submitted LOI for PCORI IDD Topical and was asked to submit full proposal</li> <li>• Rani shared that there will be a report that will come out of NASHP State Respite Summit</li> <li>• Kim shared that she is working on the Environmental Scan of caregiving research agendas for National Strategy Priority 5 grant with NAC (please share any research agendas you are aware of with Kim)</li> <li>• Ken shared one of their Exhale Programs (West Falls Center for the Arts Musical Memory Cafe) was recognized by ARCH and they are looking to expand their program</li> <li>• Sarah Swanson shared she is working with a DNP program who is implementing a respite survey to children and conducting focus groups (aligning with CDEs)</li> </ul>
<p><b>Other Discussion (ALL)</b></p>	<ul style="list-style-type: none"> <li>•</li> </ul>
<p><b>Wrap-up and Next Steps (Kim)</b></p> <ul style="list-style-type: none"> <li>• Next Meeting June 4th</li> </ul>	<ul style="list-style-type: none"> <li>• Kim to send meeting notes and recording</li> </ul>



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