



**Committee for Advancement of Respite Research  
 (CARR) Meeting  
 Notes  
 June 4, 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	X	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		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		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	X	Sarah A. Sobotka, MD MSCP Assistant Professor, Section of Developmental and Behavioral Pediatrics The University of Chicago, Chicago, IL



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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
<p><b>Introductions and Review of Agenda</b></p>	
<p><b>Updates</b></p> <p><a href="#">National Lifespan Respite Conference</a></p> <ul style="list-style-type: none"> <li>ARCH released <a href="#">National Respite Care Provider Training Replication Toolkit</a> with preliminary evaluation data</li> <li>Released Student Respite Toolkit</li> </ul> <p>ARCH recently released <a href="#">Cultural and Linguistic Competence Assessment for Respite Organizations</a> prepared in collaboration with Georgetown University National Center for Cultural Competence.</p>	<ul style="list-style-type: none"> <li>Once available, Jill will send a link to presentation recordings and slides from the National Lifespan Respite Conference held in Albany, NY in May</li> <li>Next year’s National Lifespan Respite Conference will be in Huntsville, Alabama April 1-3, 2025</li> <li>Lauren shared they are putting together a toolkit for implementing culturally-adapted dementia services for public health agencies</li> </ul>



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<p><a href="#">National Alliance for Caregiving Research Initiative</a> to advance a national research and data collection strategy focused on America’s growing community of family caregivers.</p> <ul style="list-style-type: none"> <li>• Kim is leading the development of the CARE Research Agenda and will be informing the development of CDEs for caregiving research (building off the CARR’s CDEs recommended for respite research)</li> </ul> <p><a href="#">3rd Biennial Conference on Family Caregiving Research</a>, Sept,25-27</p> <ul style="list-style-type: none"> <li>• Kim will be presenting a poster session about the CARR work</li> <li>• Kim will be facilitating a pre-conference on the National Alliance for Caregiving’s ACL-funded caregiver research initiative to share the draft CARE Agenda and solicit feedback. This will be free and by invite only.</li> </ul>	<ul style="list-style-type: none"> <li>• Let Kim know if you are interested in attending the National Alliance for Caregiving Research Initiative’s pre-conference at the Conference on Caregiving Research in Pittsburgh in September and she will get you added to the invite list</li> </ul>
<p><b>Respite Research Summit (Kim and Jill)</b></p> <ul style="list-style-type: none"> <li>• See attached overview document</li> <li>• October 28-30, 2024 from 1:00-4:30 pm ET (Virtual)</li> </ul>	<ul style="list-style-type: none"> <li>• Please see updated overview document with notes from our conversation and hyperlinks for more information</li> <li>• If you are interested in presenting or have any recommendations for potential speakers, please let Kim know.</li> </ul>
<p><b>Update on Common Data Elements Paper (Kim)</b></p>	<ul style="list-style-type: none"> <li>• Once complete, Kim will share an updated version with CARR Members for feedback.</li> </ul>
<p><b>Update on Ongoing CARR Work (Kim)</b></p> <ul style="list-style-type: none"> <li>• Funding Letter</li> <li>• National Survey Letter</li> <li>• PCORI Update</li> </ul>	<ul style="list-style-type: none"> <li>• Kim will send out letters (previously reviewed and approved by CARR) once CDE paper is finalized.</li> <li>• If you have personal connections to anyone involved in national surveys or funding opportunities we identified, please let Kim know.</li> </ul>



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<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>	<ul style="list-style-type: none"> <li>• If you are aware of any resources or potential webinar speakers related to these topics, please let Kim know.</li> </ul>
<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> </ul>
<p><b>Other Discussion (ALL)</b></p>	<ul style="list-style-type: none"> <li>• Feel free to reach out any time with questions or ideas for the CARR/ARCH.</li> </ul>
<p><b>Wrap-up and Next Steps (Kim)</b></p>	<ul style="list-style-type: none"> <li>• Kim to send meeting notes and recording</li> <li>• Respite Research Summit Run-through (TBD in late September/early October)</li> <li>• Possible follow-up meeting in September to review status of CDE paper and dissemination status.</li> </ul>

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