



**CARR Meeting  
Notes  
June 22, 2023  
2:00 pm – 4:00 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	X	Sarah Swanson, MPH Assistant Professor & Family Support Coordinator UNMC Munroe-Meyer Institute University of Nebraska Medical Center, Omaha, NE
X	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	X	Cordelia Robinson Rosenberg, PhD, RN Professor of Emeritus University of Colorado School of Medicine Aurora, CO	X	<b>Member and CARR Facilitator</b> 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	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, ARCH Consultant Lori Stalbaum and Emily Anozie, Administration on Aging, Administration for Community Living
X	Tamar Heller, PhD Distinguished Professor, Department Head Director—IDHD, Disability and Human		Sarah A. Sobotka, MD MSCP Assistant Professor, Section of Developmental and Behavioral Pediatrics The University of Chicago, Chicago, IL		



**CARR Meeting  
Notes  
June 22, 2023  
2:00 pm – 4:00 pm EST**

Development College of Applied Health Sciences University of Illinois at Chicago, Chicago, IL				
--	--	--	--	--

**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 Facilitator:</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>New logo and website layout: <a href="https://archrespite.org/">https://archrespite.org/</a></li> <li>ARCH Evaluation Mini-grants</li> <li>Lifespan Respite Grantee and Partner Learning Collaborative to help implement National Strategy respite recommendations</li> </ul>	<ul style="list-style-type: none"> <li>Read more about ARCH Innovative and Exemplary Respite Services – <a href="https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services">https://archrespite.org/provider-resources/innovative-and-exemplary-respite-services</a></li> <li>ARCH has awarded evaluation grants to 4 unique respite services recognized by ARCH as Innovative and Exemplary to advance their capabilities as research ready models and contribute to the evidence based for respite. They will be presenting their work to the CARR when completed in 10-12 months.</li> <li>The Role of Respite in the National Strategy to Support Family Caregivers: An ARCH Policy to Practice Brief - <a href="https://archrespite.org/wp-content/uploads/2023/02/Policy-to-Practice-Brief-2.pdf">https://archrespite.org/wp-content/uploads/2023/02/Policy-to-Practice-Brief-2.pdf</a></li> </ul>

	<ul style="list-style-type: none"> <li>• State Lifespan Respite Grant Activities Aligned with the National Strategy's Goals and Outcomes – <a href="https://archrespite.org/wp-content/uploads/2023/04/National-Strategy-Alignment-with-Grantee-Activities_rev-3-20-2023.pdf">https://archrespite.org/wp-content/uploads/2023/04/National-Strategy-Alignment-with-Grantee-Activities_rev-3-20-2023.pdf</a></li> </ul>
<p><b>National Strategy to Support Family Caregivers</b></p> <ul style="list-style-type: none"> <li>• Link to National Strategy: <a href="https://acl.gov/CaregiverStrategy">https://acl.gov/CaregiverStrategy</a></li> <li>• National Strategy ACL Grant FOA <a href="https://www.grants.gov/web/grants/view-opportunity.html?oppld=346925">https://www.grants.gov/web/grants/view-opportunity.html?oppld=346925</a></li> <li>• Alignment to the CARR Work Groups (See crosswalk)</li> <li>• Anything else we should do related to National Strategy?</li> </ul>	<ul style="list-style-type: none"> <li>• Cross walk of research actions in the National Strategy with CARR work group goals.</li> <li>• <a href="https://archrespite.org/wp-content/uploads/2023/06/2022-National-Strategy-CARR-Crosswalk-DRAFT-6-12-23.pdf">https://archrespite.org/wp-content/uploads/2023/06/2022-National-Strategy-CARR-Crosswalk-DRAFT-6-12-23.pdf</a></li> <li>• Plan to integrate this work into the next steps for all work groups</li> <li>• Kim suggested we could create a policy to research brief like what ARCH developed with grantees.</li> </ul>
<p><b>Work Group Updates (Kim)</b></p> <p>Work Group 1: Define and measure the value of respite</p> <ul style="list-style-type: none"> <li>• The Value of Respite Care White Paper (complete)</li> <li>• Review of CARR recommendations</li> <li>• Discuss dissemination plan (e.g., press release, webinar, 1-pager with invite to meet with key stakeholders/funders, PCORI, other ideas?)</li> </ul> <p>Work Group 2: Recommend common data elements (CDE) for respite-related research</p> <ul style="list-style-type: none"> <li>• The Value of Respite Care White Paper (in progress)</li> <li>• Review outline</li> <li>• Need to re-schedule Work Group 2 meeting (anyone else interested in joining)</li> </ul>	<p>Work Group 1 Ideas for dissemination</p> <ul style="list-style-type: none"> <li>• Community Based Organizations that provide respite (US Aging conference next week Rani could present this with her session)</li> <li>• Conferences (Kim can create slide deck for those who want to present this at conferences)</li> <li>• Gerontological Society in November</li> <li>• Conference Exhibits (Kim to create a flyer with QR code for disseminations)</li> <li>• Kim to create a list of related conferences (please send ideas to Kim)</li> <li>• ARCH working with NASHP on Respite Summit in November</li> <li>• NASHP Conference in August</li> <li>• HCBS Conference</li> <li>• BREAK Exchange and/or ARCH Webinar</li> </ul>

Work Group 3: Expand culturally appropriate research with historically underrepresented populations

- Environmental Scan (complete but ongoing)
- Resources for Culturally and Linguistically Competent Respite Research  
<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
- Additional Resources of Interest
  - *A Cultural Framework for IDD Research* by Tawara Goode  
<https://publications.ici.umn.edu/impact/35-3/a-cultural-framework-for-idd-research>
  - Racial Equity Learning Community  
<https://nccc.georgetown.edu/resources/equity-learning-community.php>

- Rani Attending: USAing (July), GSA (November), ASA (March/April)
- Respite coalitions
- Send to CARR to share with networks
- Tamar mentioned AUCD has a family special interest group and an aging special interest group that she chairs
- AUCD November Conference  
<https://www.aucd.org/conference/index.cfm/2023>
- Social media post
- NIA and NIH (expert panel contacts)
- Funders and foundations (i.e. PCORI, RWJF)
- ARCH Listserv
- ARCH Research Consortium
- If you have any additional ideas or contacts, please share!

Work Group 2

- If anyone else is interest in joining Work Group 2
- All to review and send comments and can meet 1-on-1, if needed. Would like to meet as a group in July to review/discuss.

Work Group 3

- New resources were added to the environmental scan since its release in January. Please send any additional resources you have for the Environmental Scan so this can be updated regularly
- Tawara Goode at Georgetown University National Center for Cultural Competence will begin work this Fall on developing a research guide to aid respite researchers in ensuring cultural and linguistic competence in the research they undertake. At



**CARR Meeting  
Notes**

**June 22, 2023**

**2:00 pm – 4:00 pm EST**

	<p>that time, she will hold listening sessions with CARR members to get input to inform development of the guide and ARCH will work with members to schedule these at your convenience.</p> <ul style="list-style-type: none"> <li>• The workgroup will work on incorporating guidance on community engagement to ensure that lived experience is part of the work.</li> </ul>
<p><b>Timeline for CARR Work (Jill and Kim)</b></p> <ul style="list-style-type: none"> <li>• Work Group Next Steps</li> </ul>	<ul style="list-style-type: none"> <li>• 12 months or less to finish this work (Respite Research Summit will be the culminating event for the CARR)</li> <li>• Work Group 1 and 3 to connect again in September and Work Group 2 in summer to discuss next steps.</li> <li>• Plan to schedule full committee meeting in October.</li> <li>• Kim to work on getting calendar holds out</li> </ul>
<p><b>Respite Research Summit Update</b></p>	<ul style="list-style-type: none"> <li>• Research Summit will likely be virtual in summer 2024</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>	<ul style="list-style-type: none"> <li>• We could consider hosting webinars on these topics (If you have ideas for speakers or are interested in presenting yourself 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> <li>• Feel free to reach out any time with questions or ideas for the CARR/ARCH!</li> <li>• Rani shared that John A. Hartford Foundation has funded the National Alliance for Caregiving (NAC) to do more advocacy for change and funding for change along lines of five RAISE objectives. NAC started a coalition and will be doing some</li> </ul>

prioritization, as well. Will be doing a session on advocacy at USAging conference. NAC was invited to White House! ACT on RAISE

- On June 29th from 11 am - 12 pm, the Act on RAISE Campaign will have its first virtual Advocates & Campaign Partners meeting. You can register at [https://us06web.zoom.us/webinar/register/WN\\_J\\_pSWMm9SwOvQChDVXWXEw#/registration](https://us06web.zoom.us/webinar/register/WN_J_pSWMm9SwOvQChDVXWXEw#/registration)
- Rani shared the following links in the chat: <https://www.johnahartford.org/grants-strategy/the-national-campaign-for-the-raise-national-strategy-action-toward-implementation> and <https://www.johnahartford.org/dissemination-center/view/national-alliance-for-caregiving-act-on-raise-campaign-launch>
- Sarah Swanson shared that she has a DNP student who is interested in doing evaluation of respite and is involved in HCBS settings rule.
- Sarah asked if we have had any conversations with Medicaid managed organizations as they might be a good audience to share this with. If you have connections with contacts in your state, let us know!
- Rani shared link to NASHP report <https://nashp.org/state-respite-care-and-adult-day-services-policies/>
- NASHP houses the RAISE Dissemination Center (funded by John A Hartford Foundation)
- Kim shared that she recently presented the preliminary results of the Wisconsin Respite Survey at the Wisconsin Respite Summit and the World Elder Abuse Awareness Day Conference in Arizona on the Student Respite Toolkit



**CARR Meeting  
Notes  
June 22, 2023  
2:00 pm – 4:00 pm EST**

<b>Other Discussion (ALL)</b>	
<b>Wrap-up and Next Steps (Kim)</b>	<ul style="list-style-type: none"><li>• Kim to send meeting notes and recording</li></ul>

This project is supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$1,647,597 with 75 percentage funded by ACL/HHS and \$549,200 amount and 25 percentage funded by non-government source(s). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by ACL/HHS, or the U.S. Government.