



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

Meeting Location: TEAMS

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
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	X	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		Rani E. Snyder Vice President, Program The John A. Hartford Foundation New York, NY
			Staff
			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
			X
			Casandra Firman, MS. ARCH Consultant
			Lori Stalbaum and Emily Anozie, Administration on Aging, Administration for Community Living



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

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	
<p>ARCH Updates (Jill)</p> <ul style="list-style-type: none"> • Update on ARCH Innovative and Exemplary Respite Evaluation Mini-grants • National Lifespan Respite Conference – Call for Presentations due October 30, 2023 • Comments to National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Draft 2024-2028 Long-Range Plan. See ARCH Comments • CARR comments on AHRQ Technical Brief 	<ul style="list-style-type: none"> • Mini-grantees are about half way through their evaluation projects and have done program mapping. They developed an evaluation plan and selected measures to assess caregiving well-being. Data collection in progress. Plan to present findings at the Respite Research Summit and help expand evidence base for respite. • Please consider submitting a proposal and/or joining us for the National Lifespan Respite Conference • Joe shared that NIDILRR has a funding opportunity forecasted for a research center on family support (CARR should look at this when it comes out ~January) • Kim will be presenting a NIDILRR match-making session on 11/16 on behalf of the CARR • Deadline for submitting comments to AHRQ Technical Brief is 11/6. Joe shared his disappointment that they are only focused on older adults. Kim to work on

	<p>drafting comments on behalf of CARR and will send to CARR members for review and sign on.</p>
<p>National Strategy to Support Family Caregivers</p> <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) • 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? 	<ul style="list-style-type: none"> • ARCH working as partner on Goal 3 (see ARCH press release) and submitted letters of support and will play advisory role on Goal 5 • Kim working as partner on Goal 5 and will connect with CARR work and share updates, as well. If any CARR members are interested in working with her, please let her know. • Ken suggested to keep CARR members updated on opportunities for alignment and mentioned the Changing the Care Conversation initiative – caregiving advocacy focus across multiple states. • Jill shared that ARCH has connected with Community Catalyst to share Changing the Care Conversation resources with Lifespan Respite grantees in the ARCH Learning Collaborative on Implementing 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 	<p>Work Group 1 on Value of Respite</p> <ul style="list-style-type: none"> • Sarah Sobotka suggested adding a column to the funder table that has keywords for potential funding opportunities and timeline of grant funding. • If you have any other funders you want added to the list or have key contacts please share! • Sue Peschin suggested putting the “ask” earlier in the email and then ending with “please contact me with dates/times that are convenient to meet by XXXX” (Do this for both letters)

- Review Potential Funder List and letter
- PCORI update – Meeting with Sarah Ruiz

Work Group 2: Recommend common data elements (CDE) for respite-related research

- Review draft of CDE White Paper
- Schedule Work Group meeting
- Review National Survey List and letter
- National Core Indicators (NCI) connection (Sarah Swanson)

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: 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 (coming soon)
- Other Resources?

- Sue also suggested divvying up the list among CARR members and copying them (Add a column to identify if CARR member has connection and wants to be cc'd on the emails)
- Ken said Grantmakers in Aging has a caregiving group.
- Ken said about half of all states are engaging in master plans on aging so may be good to share with those states (GIA could help with this)
- CARR members should have received a calendar invite to join PCORI meeting with Sarah Ruiz on November 3rd
- Sue suggested reviewing PCORI RFPs to familiarize ourselves prior to meeting
- Tamar said she has current PCORI funding
- Developed a 1-pager of the Value of Respite model to disseminate
- Please review dissemination opportunities list and share any others you are aware of and if you are attending any conferences, we can provide info to dissemination.
- Sue shared that NIH has a meeting in March around Alzheimer's project Act. There might be an opportunity to submit ideas for a panel or present at this. Jill has information about this. Sue can help introduce us to people there. See 2023 National Research Summit on Care, Services, and Supports for Persons Living with Dementia and Their Care Partners/Caregivers
<https://www.nia.nih.gov/2023-dementia-care-summit>

Workgroup 2: Common Data Elements

- Joe suggested making a list of what questions National Surveys currently ask related to caregiving/respite

- Kim will work on developing profiles for each survey to identify their current questions and what we would propose to change/add
- Will be helpful to know what the process is to make changes to surveys (Kim to add a column to spreadsheet)
- Sue Peschin and Dr. Rosenberg willing to join work group on drafting the white paper
- Sue suggested adding <https://www.blsa.nih.gov/> and has a contact
- Ken suggested adding something about trauma (ACEs) and can connect us with Jewish Federations of North America who is doing work around trauma and aging <https://holocaustsurvivorcare.jewishfederations.org/>
- Could also add more in outcomes around abuse/neglect/out of home placement
- Sarah Sobotka suggested adding measures around sleep/fatigue
- Plan to use CDEs with ARCH Evaluation mini-grantees, as well
- If you have tools you want included, please send them!
- Jill reminded us to look at measures used in annotated bibliography
- Susan Summers can also share the measures she has identified
- Sarah Swanson has been involved with HSRI on HCBS settings rule. Has been working closely with people at HRSI. They update the questions asked every 5 years so there is an option to suggest questions. States can also ask state-specific questions, as well. Kim to f/u with Sarah to make connection and see how we can help make suggestions to survey questions. Joe

	<p>shared he is on NCI-AD committee and timing is good. NCI-DD has family survey. Kim reminded group that we also need to ask the care recipients about their respite experiences, as well.</p> <ul style="list-style-type: none"> • Sarah Swanson also brought up issue that there is risk with people not thinking respite is needed if family caregivers are paid. • Kim to reach out to Joe Gaugler to meet with him to discuss NCI more <p>Workgroup 3 Cultural Competence in Respite Research</p> <ul style="list-style-type: none"> • ARCH shared updated Environmental Scan on Resources for advancing culturally and linguistically competent respite research • Please take poll to help identify best times for listening sessions with Georgetown NCCC in January to inform Cultural Competence Research Guide. Using the Thought Exchange Platform with AI support. • Jill shared new resources on cultural adaptations to best practice interventions for PWD and their caregivers from BOLD PHCOE on Dementia Caregiving
<p>Timeline for CARR Work (TABLED)</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"> • Tentative agenda was shared. Please provide feedback by next meeting. • If you have ideas for the respite research summit or want to present your work, please let Jill and Kim know



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

<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 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 	<ul style="list-style-type: none"> • Like idea of mini-summits • Can we get someone to give remarks from the White House administration to help draw people to attend • Considering holding it in September (October gets busy for aging community)
<p>Items for Future Discussion (ALL)(TABLE)</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>	<ul style="list-style-type: none"> • Lori from ACL wanted to share her gratitude for the work of the CARR and apologizes that she could not attend today's meeting
<p>Wrap-up and Next Steps (Kim)</p>	<ul style="list-style-type: none"> • Kim to send meeting notes and recording • Plan to possibly meet in March and June (ideally 2 before summit)

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



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

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.