



CARR Meeting Agenda January 12, 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	X	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 Pediatrics and Psychiatry University of Colorado School of Medicine Aurora, CO	X	Member and CARR Facilitator Kim Whitmore, PhD, RN, CPN Assistant Professor, College of Nursing Marquette University, Milwaukee, WI
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		Staff
				X	Jill Kagan, MPH, Director, ARCH
				X	Susan Summers, ARCH Consultant
				X	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	X	Sarah A. Sobotka, MD MSCP Assistant Professor, Section of Developmental and Behavioral Pediatrics The University of Chicago, Chicago, IL	X	Special Guest Tawara Goode National Center for Cultural Competence

Development College of Applied Health Sciences University of Illinois at Chicago, Chicago, IL			Georgetown University
		X	Emma Lynch, Research Coordinator with Sarah Sobotka

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 Facilitator: 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"> National Strategy Public Comment Learning Collaborative to help implement recommendations ARCH Mini-grants 	<ul style="list-style-type: none"> Link to National Strategy: https://acl.gov/CaregiverStrategy Kim to send public comments that were submitted to the group Ken recommended connecting to other collaboratives Rani shared: The work by that GIA-led collaborative has engaged a couple of other organizations, too, including the National Alliance for Caregiving Link to ARCH Innovative and Exemplary Practice Info: https://archrespite.org/innovative-and-exemplary-respite

<p>Ensuring Cultural and Linguistic Competence: A Guide for Respite Researchers (Tawara Goode)</p>	<ul style="list-style-type: none"> • Working on a paper and manuscript to share information from listening sessions with a diverse group of caregivers (Tawara would love recommendations on journals to submit this to) • Also did listening sessions with grantees/respice providers • Guide will include evidence-based practices in respice care related to culturally and linguistic competence (see example guide that was shared) • Planning to convene listening session with CARR and others to hear from researchers about what is working and what they struggle with. Looking to use “Thought exchange” for this.
<p>Work Group Updates (Kim)</p> <p>Work Group 1: Define and measure the value of respice</p> <ul style="list-style-type: none"> • The Value of Respite Care White Paper <p>Work Group 2: Recommend common data elements (CDE) for respice-related research</p> <ul style="list-style-type: none"> • The Value of Respite Care White Paper <p>Work Group 3: Expand culturally appropriate research with hard-to-reach or-serve populations</p> <ul style="list-style-type: none"> • Environmental Scan <p>Discuss Cultural Context</p>	<p>Cultural Context</p> <ul style="list-style-type: none"> • Important to focus on both cultural and linguistic competence • How are people prepared to enter the home, family, and cultural context, how they define respice. Respite may not align with belief systems. <p>Tawara Comments</p> <ul style="list-style-type: none"> • Work Group 1- Approaches to measure cost effectiveness are clearly defined in the literature. However, often in this literature cost effectiveness is narrowly defined. With few exceptions, costs are viewed as defined as those incurred by health care and/or human service systems, whereas the cost burden to those receiving these services and supports, their families, and communities in which they live are neither explored nor quantified using a cultural context. • Work Group 2 - Consider race, ethnicity, culture, language, multiple cultural identifies, intersectionality,

minoritized populations and communities and other relevant factors associate with diversity, equity and inclusion. What are the implication of these factors for common data elements that the work group will define?

- Work Group 3 - Revisit the believe system that underpins the terminology and concept of “hard-to-reach or serve populations”. Who is considered “hard-to-reach or underserved” and why? Members of these communities are present, highly visible yet researchers, practitioners and providers lack knowledge, skills, and in some instances resources to establish, maintain, and nurture relationships. Consider renaming this work group. Often research lacks the meaningful involvement of racially, ethnically, culturally, linguistically, and other identity groups and communities — many of which are minoritized and marginalized — in determining areas of focus of studies, salient issues and questions of relevance, research designs that use community engaged approaches, collaborative analysis (people are experts on themselves, their cultures, their interests, their communities, and their lived experience particularly within the socio-cultural contexts of systems of supports and services), and partnering in dissemination of results. What are the implications for this work group and CARR? implications for CARR? How is culturally appropriate research defined?

Group Discussion

- Rani: Make sure we explicitly include language and linguistic factors in white paper

- Susan: Tamara's comments about "hard-to-reach" and "hard-to-serve" are so important and thought provoking. I hope CARR dives deeply into this topic and can provide guidance to respite programs about how to conduct competent and relevant evaluation. Shared her experience with working with communities and asking them to define themselves and their needs. Need to check assumptions at the door when doing research (hard to do)
- Lori – asked about how we rephrase the populations we are trying to serve? Tawara – How people want to be referred to is evolving. If you know the population, name it. Important to ASK THEM how they want to be referred as. Racial/ethnic/culturally diverse and other identify groups. Consider term “minoritized communities” or “populations underrepresented in research or respite”
- Ken – Process aspect of framework may need to be looked at carefully. Not everyone identifies as caregiver. Need to look at each step in this process with linguistic and cultural competence lens.
- Sarah Sobotka - Very challenging. I wrote a paper recently with two latina coauthors- the journal editors wanted us to change to Latinx, and my colleagues preferred Hispanic...no clear or one-size answer. Think about impact of researcher and how that can change dynamics of what is shared by research participants. Different groups interpret their respite and caregiver needs differently (afraid to acknowledge unmet needs or ask for help or services). Should parents have hour limitations on how much time they provide caregiving and anything above that should be respite. (Tawara

shared this is all grounded in cultural context and power differentials and past experiences.)

- Tamar – Uses Tawara’s approach in her classes. Other groups also have evolving language: LGBTQ, gender, disabilities, Autism (need to ask people how they want to be referred to). How do you deal with people in same group having different wishes on how they want to be referred to (use both words, ask people to self-identify in survey, acknowledge different groups refer to themselves in different ways but in this paper we are using this term)
- Tawara has a racial/ethnic learning community at university and are examining the language they use and the impact it has.
- Need to incorporate principles of community-engaged research (Tawara has resources on this on their website. Communities should economically benefit from their participation and reciprocal knowledge should be honored and respected); Kim mentioned this is difficult for some researchers to do because institution/tenure track does not support community-engaged research
- Kim shared this resource designed to help empower community members when working with researchers and evaluators:
<https://ictr.wisc.edu/documents/community-guidelines-for-engaging-with-researchers-and-evaluators/>
- Also important to consider language and how we frame problems and disseminate results (Kim knows of someone from U of Minnesota)
- Tawara said there are some tribal communities who have clear guidelines for what is involved in working

with them. Ethical concerns about large grants that do not go into community.

- Tawara encouraged us to think “What’s CULTURE got to do with it” (Tina Turner style)
- Sarah Swanson mentioned there are efforts to pay family caregivers that may challenge the need for respite from some stakeholders
- Sarah Sobotka shared that paying family caregivers may actually protect family members (limit work hours)
- Possible research question: effect of paying family caregivers
- Tom: looking at research through lens of pandemic is critical (workforce is limited, increases need for respite more, remote work with family caregiving responsibilities); changes the landscape for research and programs.
- Tamar: prior to pandemic she did research on hiring families and families were unhappy to be paid for many reasons. This may be different now post pandemic. Joe also did work on this. Stigma around nursing homes and group homes being “bad” puts extra pressure on families but is hard for families who can’t get support or have other demands/jobs. Exacerbated by covid. Hard to get people with young kids to get back into office.
- Lori: ACL put out request for information and got over 1600 comments, most were caregivers and were interested in being paid. Some reported having lost employment and SS. NASHP did analysis of these comments - <https://nashp.org/in-their-own-words-family-caregivers-from-across-the-country-share-their-priorities-and-recommendations/> 46% of respondents

	<p><i>(647) responded that respite options are needed actions to address caregiver priorities (see Table 2).</i></p> <ul style="list-style-type: none"> • Rani – topic of paid family caregivers has been getting increased attention at national level. Primarily Medicaid funded and VA. • Sarah Sobotka - Great question, Sarah - IMO paying family caregivers is acknowledging current efforts which could be delivered by home nursing but aren't, and helps to support families when employment must be deferred due to nursing needs of child. Unmet respite needs remain despite efforts to pay families for care delivered. • Ken - Rani, in NYS some AAAs did (and still may) use consumer directed care as an alternative to home care agencies for their in-home respite care programs, due to aide shortages. state and title III dollars. I could provide a bit more info. on it if you'd like.
<p>Timeline for CARR Work (Jill and Kim)</p> <ul style="list-style-type: none"> • Work Group Next Steps • Respite Summit (Spring or Fall 2024) 	<ul style="list-style-type: none"> • Please review the CARR documents and provide any feedback to Kim by Friday, January 20th so she can work on revisions. • If you are interested in being a coauthor of the white paper, please let Kim know. • Next work group meetings in spring • Next full CARR meeting in summer
<p>Items for Future Discussion (ALL)</p> <ul style="list-style-type: none"> • Pragmatic trials • Community-engaged research 	<ul style="list-style-type: none"> • If there are other topics of interest the group would like to discuss, please share with Kim.
<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).



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	<ul style="list-style-type: none"> • Feel free to reach out any time with questions or ideas for the CARR/ARCH! • Ken Update: Our exhale respite pilot projects are all launching this year. Here's a link on our exhale respite program and the project. We also have 3 current pilots that are working toward ARCH exemplary services recognition! https://tpi.org/exhale-the-family-caregiver-initiative/ Exhale - The Philanthropic Initiative
<p>Other Discussion (ALL)</p>	<ul style="list-style-type: none"> • Ken was on webinar from AARP NY and they are talking about how to better engage respite. May want to connect with them and others who are doing work in this area. How do we engage with these other groups. • Jill shared that ARCH/CARR does want to engage with other groups • Kim shared may be time to put out press release and invite partners to respite research summit. Unique window of opportunity with covid awareness of caregiving issues and national strategy. • Kim and Jill to document initiatives/stakeholders and can consider pushing out white paper and inviting to summit.
<p>Wrap-up and Next Steps (Kim)</p>	<ul style="list-style-type: none"> • Kim to send meeting notes and recording • Will follow-up to schedule CARR Work Group meetings in spring and full meeting in summer

This project is supported, in part by grant number 90LRLT0001, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.