Committee for Advancement of Respite Research

Advance respite research with activities and Innovations to develop an evidence base for respite
Welcome and Introductions

ARCH Staff

CARR Members
# Overview of Agenda

- ARCH Updates
- National Strategy to Support Family Caregivers: Research Implications
- Works Group Updates
- Timeline for CARR Work
- Respite Research Summit
- Items for Future Discussion
- CARR Member Updates
Update on ARCH Evaluation Mini-grants

- Innovative and Exemplary Respite Services
  Read more about ARCH Innovative and Exemplary Respite Services
  archrespite.org/provider-resources/innovative-and-exemplary-respite-services

- Mini-Grant awards for evaluation

- Goal: To prepare well-defined respite models for more rigorous research with goal for replication
2024 National Lifespan Respite Conference

- May 21-23, 2024, Albany, NY
- ARCH Co-hosts: NY State Caregiving and Respite Coalition and the NY State Office for the Aging

- Call for Presentations Deadline: October 30, 2023
- Consider Research Track
- Read more and submit online: https://archrespite.org/2024-national-lifespan-respite-conference
National Institute on Disability, Independent Living, and Rehabilitation Research

- ARCH comments submitted to NIDILRR’s Draft 2024-2028 Long-Range Plan  [https://archrespite.org/arch-nidilrr-comments/](https://archrespite.org/arch-nidilrr-comments/)

- Virtual matchmaking sessions to connect ACL/NIDILRR partners with common research interests
AHRQ is seeking comments on a plan for a Technical Brief that will provide an evidence map that summarizes service categories of HCBS, effectiveness of these interventions for specific conditions, and quality measures relevant to HCBS.

This Technical Brief will also identify gaps in the evidence base.

This work will help inform policy development by ACL and the Centers for Medicare & Medicaid Services.
National Strategy to Support Family Caregivers

- National Strategy ACL Grants Awarded
  - 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 (USAging)
  - Goal 4: Ensure financial and workplace security for family caregivers. (Not yet funded – new FOA issued)
  - 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?
Work Group 1 Update
Define and measure the value of respite

- Measuring the Value of Respite Care White Paper and Framework (complete)
- Review dissemination materials
  - How have you been disseminating the paper?
- Review list of potential funders and letter
- PCORI connection update
Work Group 2 Update
Recommend common data elements (CDEs) for respite-related research

- Review draft of Common Data Elements (CDE) White Paper
- Schedule Work Group meeting
- Review National Survey list and letter
- National Core Indicators (NCI) connection
Work Group 3 Update
Expand culturally appropriate research with historically underrepresented populations

- Environmental Scan (complete but ongoing) - Resources for Culturally and Linguistically Competent Respite Research

- Update on *Ensuring Cultural and Linguistic Competence: A Guide for Respite Researchers*: Listening Session with CARR in January

- Additional Resources
  - PHCOE on Dementia Caregiving Update on resources for Cultural Adaptations of Services
CARR Work Group
Next Steps
Respite Research Summit

- **Format**
  - Consider doing 3 virtual mini-summits

- **Tentative Agenda**
  - Formation of CARR Priorities/National Strategy Alignment
  - Panel Presentation on ARCH Innovative and Exemplary Respite Evaluation Findings
  - Respite Research Guide on Cultural and Linguistic Competence
  - Measuring the Value of Respite and Framework
  - CDE Paper
  - Emerging research/evaluation
  - Participant input through small group roundtable discussions
Ideas for Future Discussion

- Pragmatic Trials
- Community-Engaged Research
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
Contact Information

Kim E. Whitmore, PhD, RN, CPN
Assistant Professor
College of Nursing, Marquette University
kimberly.whitmore@marquette.edu

Jill Kagan, MPH
Director
jkagan@archrespite.org

ARCH National Respite Network
and Resource Center
archrespite.org

Lifespan Respite Technical Assistance Center

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.