

# Committee for Advancement of Respite Research

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

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*October 23, 2023*

# Welcome and Introductions

ARCH Staff

CARR Members



# Overview of Agenda

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ARCH Updates

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National Strategy to Support Family  
Caregivers: Research Implications

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Works Group Updates

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Timeline for CARR Work

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Respite Research Summit

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Items for Future Discussion

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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](http://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://archrespice.org/arch-nidilrr-comments/>
- Virtual matchmaking sessions to connect ACL/NIDILRR partners with common research interests



# Agency for Healthcare Research and Quality (AHRQ) Technical Brief Comments

- 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



# CARR Member Updates

- 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

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## Lifespan Respite Technical Assistance Center

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