



Respite Research Consortium Update January 2019

In this update, ARCH is pleased to share:

- A **Funding Opportunity Announcement** from the National Institute on Nursing Research that may be of interest to researchers in the Consortium;
- an update from the **Robert Wood Johnson Foundation's Evidence for Action** program for Investigator-Initiated Research;
- respite outcomes from **National Family Caregiver Support Program Outcome Evaluation**;
- an announcement about the **ARCH Respite Research Summit** to be held in June 2020, in Madison, WI, in collaboration with the International Short Break Conference hosted by the WI University School of Nursing, the Respite Care Association of WI, the International Short Break Association, and ARCH;
- the **Break Exchange**;
- **Research on Family Caregiving Support in the United States: A Strategic Research Plan** from the Family Support Research and Training Center (FSRTC); and
- the final **ARCH Annotated Bibliography**.

Invitation to Researchers to Review the FOA PA-18-150 Promoting Caregiver Health Using Self-Management

ARCH is pleased to bring to your attention a Funding Opportunity Announcement (FOA) [FOA PA-18-150](#) from the National Institute on Nursing Research (NINR), one of the National Institutes of Health. The title of the FOA is **Promoting Caregiver Health Using Self-Management (R01 Clinical Trial Optional)**. This FOA might be of interest to members of the Respite Research Consortium as an opportunity for investigators to implement a research project aligned with the Respite Research framework recommended by ARCH's Expert Panel in its [final report](#).

Eligibility. Although this announcement has been released as an R01 Research Project Grant (R01 clinical trial optional), eligibility is NOT restricted to institutions of higher education. Other eligible potential applicants include 501(c)(3) nonprofits, for-profit small businesses, non-federal government agencies, Indian/Native American tribal governments, and others.

Timelines. Note that this is a reissuance of PA-17-062, now identified as PA-18-150. NIRN will be receiving applications relating to this FOA through May 8, 2020. This application timeframe provides sufficient time to construct a thoughtful and rigorous research proposal.

FOA Highlights and Summary and Relevance to Respite Research. In the words of the FOA: “The purpose of this initiative is to stimulate research in promoting caregiver health using self-management. Caregiving is an important science area since the number of people living longer with chronic conditions is growing. Informal caregivers (lay caregivers) are defined as unpaid individuals (spouses, partners, family members, friends, or neighbors) involved in assisting others with activities of daily living and/or medical tasks. Formal caregivers are paid, delivering care in one’s home or care settings (daycare, residential care facility). This FOA focuses on informal caregivers.”

The Background Statement at the beginning of Part 2, Full Text of Announcement, identifies many of the challenges faced by caregivers that are identified by ARCH’s Expert Panel on Respite Research and presented in the final report from the Expert Panel’s work. The Report addresses many of these issues in its recommendations on conducting prospective research on respite care.

Possible research topics identified in the FOA include: “caregiving that address challenges, barriers, and unique situations related to caregiver’s age, gender, or socioeconomic status and promote caregiver health,” “interventions [that] are efficacious and effective for self-management of caregivers across chronic conditions,” and/or a “mechanism of action for self-management interventions that work to affect caregiver health outcomes.”

Please NOTE: This FOA is an NIH/NINR announcement, so the scientific rigor of your design must be evident. We encourage you to review this FOA and consider applying for a rigorous research project on caregiver self-management in the form of respite care. If this FOA aligns with your interests related to research on respite care, we encourage you to contact [Dr. Ray Kirk](#) with ARCH for a more in-depth discussion about NIRN and the process of submitting a grant application. We will treat any such conversations with the strictest of confidence and will not share your interest in this FOA with any other researchers who make inquiry, unless you ask us to do so.

Update from Evidence for Action (E4A) – Investigator-Initiated Research

The Robert Wood Johnson Foundation’s E4A will review ideas for research that align with their purpose to fund rigorous research designed to assess the causal impact of programs or policies

on health outcomes. If you have a respite research idea, [read the Call for Proposals and submit your Letter of Intent](#).

E4A also has a Matching Service that facilitates partnerships between researchers and organizations implementing community-level initiatives to design and conduct a rigorous evaluation of those interventions. The service is provided by [Accelerating Collaborations for Evaluation \(ACE\)](#), a team based at Johns Hopkins University and led by Drs. Albert Wu, Jill Marsteller, and Christine Weston.

Outcome Evaluation of the National Family Caregiver Support Program (NFCSP)

The Administration for Community Living (ACL) released the [Outcome Evaluation of the National Family Caregiver Support Program](#) on December 6. The research questions that were explored were described in the [December issue](#) of ARCH Quick News Update.

Survey response data were collected by telephone from a large (N = 1568) nationally representative sample of NFCSP client caregivers who had received services under NFCSP, from a comparison group of caregivers who do not receive NFCSP services, and from a sample of care recipients (CRs) of caregivers in the two groups. Six-month and 12-month follow-up surveys also were conducted. This was the first national longitudinal survey of caregivers designed for evaluating the NFCSP. The five caregiver outcome measures that were the focus of this evaluation were: mental health, physical health, caregiver burden, caregiver satisfaction, and caregiver confidence. The evaluation was designed and conducted by Westat for ACL.

Key Respite Findings

Key among the evaluation's findings are important insights into the value of respite in reducing caregiver burden and that education and training services can lead to greater caregiver confidence over time. One key finding regarding respite was that, on average, NFCSP caregivers who received 4 or more hours of respite care per week had a decrease in self-reported burden over time, while the comparison caregivers experienced an increase in self-reported burden. In addition, among caregivers who used NFCSP respite care, as the respite hours per week increased so did the probability of a more favorable response regarding caregivers' perception that services helped them continue caregiving, an important factor in delaying or preventing the institutionalization of the care recipient. Additional data were collected on caregivers' use and perceived helpfulness of NFCSP respite care.

The full report provides detailed information on the measures employed, including the PROMIS global mental health instrument, Zarit’s caregiver burden scale, and caregiver satisfaction and confidence questions instructed by the evaluators.

The findings are informative to the issue of dose/response of respite service (i.e., frequency, intensity, and duration of services). The report contains much additional information on demographics, health conditions, behaviors of caregivers and care receivers, hospitalizations and institutionalization. This information is potentially informative to researchers designing outcome studies in any aspect of respite care. Depending on the design and the research questions, these variables may manifest as intervening variables or as dependent variables associated with the service or intervention.

In addition to the evaluation report, additional information is available on the evaluation and its interpretations. On November 28, 2018, the Administration for Community Living held a webinar with the Westat Evaluation team to preview the findings. The [webinar slides](#) provide a useful summary of the principal findings from the report. Also available are [responses to attendee questions](#) posed during the webinar. The two-part NFCSP evaluation also includes a previously released [process evaluation report](#), and examples of assessment tools collected from State Units in Aging that are available on request.

2020 Respite Research Summit



ARCH is pleased to announce that we will join the University of Wisconsin School of Nursing and the Respite Care Association of Wisconsin to host the **2020 International Short Break Association Conference** in Madison, WI, in June 2020. ARCH is a founding member of the International Short Break Association (ISBA) which hosts the conference every other year. In

conjunction with the International Short Break Conference, ARCH will convene a **Respite Research Summit** to bring together researchers and funders in the ARCH Research Consortium, members of the Expert Panel on Respite Research, and international researchers to explore the current state of respite research and the impact of the Expert Panel’s recommendations on advancing the development of an evidence-base for respite. The Respite Research Summit will be held on June 19, 2020, at the Monona Terrace Convention Center in Madison, WI.

The Break Exchange

The BREAK (Building Respite Evidence and Knowledge) has been started by Dr. Kim Whitmore, Assistant Professor of Nursing at the University of Wisconsin and her colleagues with ISBA. The Exchange is an international group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care. To join the Exchange and learn more about it, visit the [Facebook page](#).

Research on Family Caregiving Support in the United States: A Strategic Research Plan

The Family Support Research and Training Center (FSRTC) has just released [Research on Family Caregiving Support in the United States: A Strategic Research Plan](#). This report provides a roadmap for future research on family support for families of people with disabilities and who are aging. The development of the research recommendations involved multiple stakeholders including family caregivers, people with disabilities, health and social welfare professionals, policymakers, and researchers. The report suggests seven areas in need of greater research attention, including respite and cites the report of the ARCH Expert Panel on Respite Research.

ARCH Annotated Bibliography

In November, ARCH released the 4th edition of the [Annotated Bibliography on Respite and Crisis Care Research](#). This edition contains information on thirty studies published since the release of the 3rd edition.

Thank you for your interest in the Respite Research Consortium. We will continue to keep you updated on any future activities or research funding opportunities. Please let us know if you have any questions.