In this update, ARCH is pleased to share:

- 2020 ARCH Respite Research Summit and the International Short Break Conference
- Of Interest.... Research Agendas Focused on Caregiving and Respite
- New Research Initiatives in Caregiving and Family Support
- Evidence for Action Ongoing Funding Opportunity
- Join the BREAK Exchange!

2020 Respite Research Summit and the International Short Break Conference

You are invited to attend a one-day Respite Research Summit on June 19, 2020, in Madison, WI. The Summit is intended 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 globally and the impact of the Expert Panel’s recommendations on advancing the development of an evidence-base for respite. We expect to release a program agenda for the Summit in the coming weeks. Seating for the Summit will be limited, so please register early! ARCH is convening the meeting with support from the Administration for Community Living through the Lifespan Respite Technical Assistance Center and the John A. Hartford Foundation.

Register for the International Short Break Conference and/or the Respite Research Summit at www.isba.me/registration.

The Research Summit will be held in conjunction with the International Short Break Association (Respite) Conference to be held June 16-18, 2020, at the Monona Terrace Convention Center in Madison, WI. ARCH joins the International Short Break Association (ISBA), the University of Wisconsin School of Nursing and the Respite
Care Association of Wisconsin to host the event. ARCH is a founding member of the International Short Break Association (ISBA) which hosts the conference every other year.

**Of Interest….Other Research Agendas Focused on Caregiving and Respite**

**Toward a Research Agenda on the Impact of Dementia upon Carers of Adults with Intellectual Disability.** The National Task Group on Intellectual Disability and Dementia Practices (the NTG) identified needed research related to caregivers of adults with intellectual disabilities (ID). Individuals with ID are at risk for developing early-onset dementia. The recommendations were submitted to NIH-NIA for consideration at the Second National Research Summit on Care, Services, and Supports for Persons with Dementia and their Caregivers. The NTG recommended three focal areas for the summit to consider: 1) the effect of behavioral and psychological symptoms of dementia on carers, 2) challenges for carers of adults with intellectual disability when dementia becomes evident, and 3) barriers that carers face when accessing supports. They suggest research about what situational factors facilitate or compromise efficient in-home care, such as targeted training, extending home modifications, providing respite, or other relief sustaining strategies. Janicki, M.P., Jokenin, N.S., Marsack Topolewski, C., Keller, S.M. *Journal for ReAttach Therapy and Developmental Diversities*. 2019 Sep 08; 2(1):51-60. [https://doi.org/10.26407/2019jrtdd.1.18](https://doi.org/10.26407/2019jrtdd.1.18)

In the last Research Consortium Update (9/19), we shared ARCH’s recommendations for research related to respite for caregivers of persons with dementia that were submitted to Dementia Summit organizers at NIH-NIA. The National Research Summit Care, Services, and Supports for Persons with Dementia and their Caregivers will be held March 24-25, 2020, at the Natcher Conference Center in Bethesda, MD.

**NADSA Research Positioning Statement and 5 Year Plan: August 2019.** The Research Committee of the National Adult Day Services Association (NADSA), the nonprofit trade association of Adult Day Services providers, released a research agenda in August 2019 that lays out a plan for how research in the field of Adult Day Services (ADS) should be positioned and developed in the coming years. The purpose of the statement is:

- To facilitate translation and dissemination of relevant research to improve the delivery of adult day services (ADS) and the quality of life of people supported in ADS and their caregivers;
- To identify research focus areas in ADS in collaboration with providers and research partners;
- To promote research that quantifies impact of ADS and supports increased utilization and expands the role of ADS in the care continuum; and
• To continually evaluate and update the actions and recommendations herein to demonstrate the evolving interdependence of ADS and research.

The statement recommends research priorities for ADS research, promotes standardized outcome measures as well as collaboration among ADS stakeholders in data utilization; and supports translation of research data to practice. Read the statement.

New Research Initiatives in Caregiving and Family Support

National Rehabilitation Research and Training Center on Family Support. The National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) at ACL has awarded a Rehabilitation Research and Training Center (RRTC) project grant for five years to the University of Pittsburgh Center for Caregiving Research, Education, and Policy to support research towards advancing family caregiving support for people with disabilities.

The new National Rehabilitation Research and Training (RRT) Center on Family Support will conduct research that addresses family support for persons with disabilities across the lifespan to improve care, health, and quality of life outcomes. The aim is to advance the science of family support services that are person- and family-centered, promote choice and control for persons with disabilities, and are scalable and sustainable in the community.

The Center’s goals:

• Advance state-of-the-science research in caregiving, rehabilitation, and digital self-management support for persons with disabilities and their family caregivers with the goal of maintaining independent living in the community,
• Train health and rehabilitation providers and researchers in family caregiving science and practice,
• Leverage findings from center research projects to advance the capacity of healthcare and public health systems to deliver high-quality, tailored support to family caregivers of persons with disabilities,
• Utilize dynamic mechanisms to translate and disseminate knowledge to persons with disabilities, family caregivers, policymakers, service providers, researchers, employers, and other key stakeholders.

Edward R. Roybal Centers for Translational Research on Dementia Care Provider Support.

Four out of thirteen Edward R. Roybal Centers for Translational Research in the Behavioral and Social Sciences of Aging funded by NIH are focused on development of interventions to improve
and support dementia care. Two of these that were recently awarded NIH grants will be conducting caregiver focused research:

The Roybal Center for Social Ties and Aging Research (STAR), a joint initiative between the UR School of Nursing and the Department of Psychiatry at the University of Rochester Medical Center, will focus on fostering collaboration among researchers to make a significant impact on the problem of social disconnection in older caregivers of individuals with Alzheimer’s Disease and other related dementias (ADRD). The Center will be funding pilot studies through its annual Pilot Award Program. Requests for proposals will be announced in the next several months.

Emory University’s Nell Hodgson Woodruff School of Nursing received a Roybal Center grant to provide support to investigators across the nation to conduct NIH Stage I-III intervention research that will enhance the context-specific role-mastery of informal caregivers of persons living with Alzheimer’s disease and similar illnesses. Emory’s center, the Roybal Translational Research Center to Promote Context-Specific Caregiving of Community-Dwelling Persons Living with Alzheimer’s Disease or Related Disorders, will support research pilot projects that are designed with caregivers/consumers from various caregiving settings.

Funding Opportunity

**Ongoing from Evidence for Action (E4A) – Investigator-Initiated Research.** An ongoing opportunity from the Robert Wood Johnson Foundation’s Evidence for Action (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 about more information for applicants.

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,

**Join the Break Exchange!**

The BREAK (Building Respite Evidence and Knowledge) Exchange is an international group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care. The BREAK Exchange was established in 2018 by the University of Wisconsin – Madison School of Nursing in collaboration with the ARCH National Respite Network and the International Short Break Association. Currently, there are more than
100 members from more than 10 countries in the Exchange. Dr. Kim Whitmore, at the University of Wisconsin School of Nursing recently was awarded a grant from the University of Wisconsin - Madison Global Health Institute to advance BREAK Exchange activities. Members of the BREAK Exchange can:

- CONNECT with a global network of researchers, respite providers, agencies, and individuals.
- LEARN about evidence-based respite care practices and research happening around the world.
- SHARE evidence-based practices or research with international partners.
- COLLABORATE on an evaluation or research project through opportunities to leverage the Exchange to identify a potential partner for your next research project.

Learn more about the BREAK Exchange. To join the BREAK Exchange please visit: breaknursing.wiscweb.wisc.edu/get-involved.

Thank you for your interest in the Respite Research Consortium. Past updates can be found here.

ARCH also publishes information about relevant caregiving and respite research in the monthly ARCH Quick News Update. Please feel free to subscribe to the News Update and read past issues.

See also ARCH’s Annotated Bibliography.

We will continue to keep you updated on any future Research Consortium activities as well as research news and funding opportunities. Please contact Ray Kirk at ARCH if you have any questions.

This project was supported, in part by grant number 90LT0002, 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 Administration for Community Living policy.