Research Consortium Update
October 2018

This is an update on implementation of the respite research recommendations from the final report of ARCH’s Expert Panel on Respite Research. The ARCH National Respite Network and Resource Center houses the federally funded Lifespan Respite Technical Assistance Center. ARCH continues to build a Research Consortium that links funders with researchers to encourage new studies that will help to strengthen the evidence-base for respite services for family caregivers. We are pleased to share the progress we have made and let you know about some exciting prospects for the future.

Highlights of Recent Accomplishments/Activities

For the past year, ARCH Senior Consultant and facilitator of the ARCH Expert Panel on Respite Research, Dr. Ray Kirk, has been working with the Health Foundation of Western and Central New York to help facilitate the formation of a research team to develop a research proposal using the Expert Panel’s framework and suggested outcomes. In June, the Health Foundation of Western and Central New York (HFWCNY) announced funding for a respite study of caregivers of persons who have physical, intellectual, or cognitive disabilities, and are consumers of respite services. The study investigators are Dr. Tiffany Washington, University of Georgia, Dr. Sheryl Zimmerman, University Kenan Distinguished Professor and co-Director of the Program on Aging, Disability, and Long-Term Care, Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, and Dr. Tom Caprio Associate Professor in the Departments of Dentistry, Medicine, Nursing, and Public Health Sciences at the University of Rochester. The New York State Office for the Aging will assist with recruitment of family caregivers.

The research team will recruit respite consumers to respond to telephone respite questionnaires and participate in focus groups at the 2019 ARCH National Lifespan Respite Conference in Buffalo, New York. The project, titled Building Evidence for Respite, will examine respite dose (i.e., frequency, duration, and intensity of respite) and its relationship to caregiver burden, family well-being, and care recipient quality of life; and 2) the relationship of contextual factors (e.g., ethnicity, environment, care situation, nature of social support) to caregivers’ access to and desire for respite. Using a mixed-methods research design, the goal of the proposed research is to deepen the understanding of respite’s impact and be responsive to research recommendations outlined in the ARCH National Respite Network and Resource Center’s report on respite research.
In addition to this commitment of foundation funding from HFWCNY for research based directly on the recommendations of the Expert Panel, we have initiated interest among other researchers who have successfully completed research with relevant respite findings, are undertaking new studies with funding from NIA, or are seeking funding for newly generated ideas.

Highlights are:


2) Research consortium member, **Dr. Rebecca Utz**, Associate Professor and Director of Graduate Studies, Department of Sociology; Director, Health Society & Policy program and Co-Director, Consortium for Families & Health Research, University of Utah has been funded by the National Institute on Aging to undertake an examination of Virtual Coaching to Maximize Dementia Caregivers’ respite time-use. This is the first intervention designed to maximize caregivers' use of respite time in order to improve immediate and personal assessments of time-use as well as global subjective well-being outcomes. Her long-time research partner, Dr. Dale Lund, who recently retired, served on the Expert Panel on Respite Research.

3) **ARCH Research Consortium member, Dr. Kim Whitmore at the University of WI School of Nursing**, in collaboration with ARCH, the Respite Care Association of Wisconsin, and Shared Care Scotland, submitted a grant proposal to the Robert Wood Johnson Foundation to investigate international respite models that reduce social isolation of family caregivers/child care recipients. Research protocols referenced the respite research framework developed by ARCH’s Expert Panel on Respite Research. While this study was not funded, the principals will be resubmitting the proposal to other funders. The specific aims of the study would be to: 1) Adapt, implement and evaluate best respite care practices identified from the UK in the US. Measures of social support will be used to evaluate the effectiveness of the respite care programs in both the UK and
US; and 2) Establish an international knowledge exchange in order to learn from and with other countries. Success will be measured by the internationally developed and tested, Partnership Assessment Tool. Dr. Whitmore also recently published the following article: Whitmore, K. & Snethen, J. (2018). Respite care services for children with special healthcare needs: Parental perceptions. Journal for Specialists in Pediatric Nursing. Advance online publication. doi: 10.1111/jspn.12217.

**2020 Respite Research Summit**

The University of Wisconsin School of Nursing and the Respite Care Association of Wisconsin will 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. Once ARCH’s continuation funding from the Administration for Community Living is confirmed for FY 2019, we will be announcing as a third cohost of the event. In conjunction with the International Short Break Conference, ARCH plans to hold the 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.

**Annotated Bibliography**

This month, ARCH will release the next edition of the Annotated Bibliography on Respite and Crisis Care Research. We will forward it to you when it is finalized.

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.