In this update, ARCH is pleased to share:

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- Virtual Coaching to Maximize Respite Time-Use for Alzheimer’s Caregivers: Development & Testing of the TLC, Time for Living & Caring, Intervention
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Building Evidence for Respite - Using the Expert Panel on Respite Research Framework

To advance the recommendations of the ARCH Expert Panel on Respite Research, the Health Foundation for Western and Central New York is funding a research proposal that was designed using the Expert Panel’s framework and suggested outcomes. The study will examine respite use of caregivers of persons who have physical, intellectual, or cognitive disabilities in Upstate New York. The lead study investigator is Dr. Tiffany Washington, University of Georgia, and the study team includes 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 and the New York State Caregiving and Respite Coalition has been assisting with recruitment of family caregivers.
To date, identified family caregivers have been recruited and interviewed via telephone respite questionnaires and these interviews are ongoing. In addition, caregivers participated 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.

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**Short Breaks for Carers: A Scoping Review from the UK**

**Shared Care Scotland** commissioned a Scoping Review to better understand what research evidence tells us about the impact of short breaks (respite) for carers. This work was completed by researchers at Bangor University, Bangor, Gwynedd, North Wales. The initial literature search included a broad range of carer groups. Due to the large volume of literature identified, the focus was refined to carers for older people, including people living with dementia. **Diane Seddon, Centre for Ageing and Dementia Research, School of Health Sciences, Bangor University** who is a member of the ARCH Research Consortium, provided highlights from the scoping review that can be found here.

Findings from this Scoping Review will support the work of a UK Research and Practice Development Group on Short Breaks for Carers. Members of the Group will disseminate the findings at several events, including the UK Dementia Congress 2019 and the Wales Carers Officers Learning and Improvement Network Meeting 2019. Researchers from this effort are expected to provide an update on this work at the ARCH Respite Research Summit for June 2020 in Madison, WI, in conjunction with the International Short Break Conference. (see Research Summit below).

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Virtual Coaching to Maximize Respite Time-Use for Alzheimer’s Caregivers: Development & Testing of the TLC, Time for Living & Caring, Intervention

Researchers at the University of Utah were awarded funding from the National Institute on Aging (NIA) for a project entitled “Virtual Coaching to Maximize Respite Time-Use for Alzheimer’s Caregivers: Development & Testing of the TLC, Time for Living & Caring, Intervention.” Dr. Rebecca Utz, the project’s principle investigator, is a member of the ARCH Respite Research Consortium. The TLC intervention uses goal-setting and goal-review techniques to guide caregivers to use respite more consistently and more effectively. An interdisciplinary research team is currently re-developing their intervention from a pen-and-paper, facilitator-delivered support program, to a fully online delivery. They are working closely with a Community Advisory Board, comprised of caregivers, respite providers, and leaders of diverse communities to ensure that the created technology meets the needs and interests of those who it will serve. The TLC program will be fully prototyped and ready for clinical trial in late 2020. For more information, contact PI Dr. Rebecca Utz, rebecca.utz@utah.edu.

National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) -- 2018-2023 Long-Range Plan

In January of this year, NIDILRR’s released its 2018-2023 Long-Range Plan. The plan presents a five-year agenda that will guide the agency's upcoming research agenda to advance work being done in applied disability, independent living, and rehabilitation research. The plan was developed after soliciting and reviewing written comments and public testimony at six in-person regional listening sessions to “better understand the experiences and perspectives of people with disabilities, the providers who serve them, caregivers and other support system members (both formal and informal), policymakers, and academic researchers.” In this plan, NIDILRR proposed a new community living and participation research agenda to support new knowledge and products that can be used to increase community living and participation among people with disabilities. In this research domain, the agency identified Family Caregivers as one of five areas of potential investment in new research:

Family caregivers. Sponsoring the development and implementation of a research agenda on family caregivers of people with disabilities. Research in this area can be used to promote the community living outcomes of people with disabilities by better understanding and providing for the economic, social, and health-related well-being of their family caregivers.

Read more about the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR). Research funding opportunities from NIDILRR are available on grants.gov.
2020 National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers

In June, ARCH responded to a widely distributed Invitation for Input on the 2020 National Research Summit on Care, Services, & Supports for Persons with Dementia and their Caregivers from the National Institute on Aging (deadline for submitting comments was June 2019). The Summit will be held March 24-25, 2020, at the Natcher Conference Center in Bethesda, MD, and is designed as the second in what is to be a series of biannual summits offered by NIH-NIA that will focus on services and supports for people with dementia and their caregivers.

The ARCH response recommended that “conference planners include reference to the need for more research on the benefits of respite care for family caregivers as a stand-alone service, or a service that can be offered in conjunction with other services (e.g., caregiver skills training and education; caregiver support groups and mental health services; social engagement and therapeutic and medical services provided by professional caregivers) in a comprehensive plan of care for persons living with dementia. The logic of this recommendation rests squarely on the potential of respite to increase or maintain caregivers’ ability to provide competent and compassionate care for the longest period of time, with the least amount of stress, burnout, and detrimental impact on caregivers’ health and well-being. Supporting caregivers in this fashion also has the potential to improve the quality of life of the person living with dementia and decrease the risk of unnecessary hospitalization or premature institutionalization of the person living with dementia.” Read the full ARCH response.

The first National Research Summit on Care, Services, and Supports for Persons with Dementia and Their Caregivers was a 2-day meeting in October 2017 sponsored by the U.S. Department of Health and Human Services and private sector organizations. You can view the final Summit report with research recommendations and the archived videos of the event here.

Research Track at the National Lifespan Respite Conference in Buffalo, NY Features Research Consortium Members

In May 2019, ARCH hosted the National Lifespan Respite Conference in Buffalo, NY in collaboration with the New York State Caregiving and Respite Coalition and the New York State Office for the Aging. The program featured a research track in which two members of the Research Consortium presented their research:

1) Tiffany R. Washington, PhD, MSW, Assistant Professor, School of Social Work, University of Georgia, Athens, GA and Erin Beasley, B.S.Ed., Director of Operations, Athens Community Council on Aging, Athens, GA

Partners in Caregiver Respite Support: A Community-University Case Study
This case study described in this session is about a partnership between a research-intensive university and a non-profit organization focused on aging services to provide respite support to caregivers. Houseguest, a caregiver respite program, was designed using a community-engaged scholarship model of integrating research, teaching, and service.

2) **Kim Whitmore, PhD, RN**, Assistant Professor, School of Nursing, University of Wisconsin – Madison, Madison, WI

**Meeting the Unmet Respite Care Needs of Families of Children with Special Healthcare Needs**

Results of a study examining factors associated with unmet respite care needs in 2,518 families of children with special healthcare needs were presented. Families of children with autism spectrum disorder, whose child has high caregiving demands and functional limitations, and whose family perceives higher family fiscal burden are at highest risk for unmet respite needs.

**Nora O'Brien-Suric, President, Health Foundation for Western and Central New York,** addressed the opening plenary session of the conference promoting the idea that everyone involved in the provision of respite care, from administrator to practitioner, should seek ways to contribute to building the evidence base for respite care, and noted ARCH’s role in advancing the recommendations of the Expert Panel on Respite Research.

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**2020 Respite Research Summit and the International Short Break Conference**

On June 19, 2020, ARCH will convene a one-day **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 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 tentative agenda for the Summit in the coming weeks. Please join us! Seating for the Summit will be limited, so please register early!

Register for the International Short Break Conference and/or the Respite Research Summit at [www.isba.me/registration](http://www.isba.me/registration).
The Research Summit will be held in conjunction with the 2020 International Short Break Association (Respite) Conference to be held June 16-19, 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 at the Monona Terrace Convention Center in Madison, WI.

THE CALL FOR ABSTRACT PRESENTATIONS FOR THE INTERNATIONAL SHORT BREAK CONFERENCE IS OPEN UNTIL SEPTEMBER 30, 2019. SUBMIT YOUR ABSTRACT HERE: WWW.ISBA.ME/ABSTRACTS/

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.

On May 15, 2019, BREAK Exchange hosted an introductory webinar to introduce the team, the mission, and the plan for the future. The webinar can be found here. If you missed this one and would like to interact with BREAK Exchange organizers, another introductory webinar to share
more information about the project will be held on September 18, 2019. The webinar will be held here. For the webinar time and more information, please contact break.exchange@son.wisc.edu.

Last May, Dr. Whitmore presented with Casandra Firman and Dr. Susan Janko Summers with ARCH on the BREAK Exchange at the National Lifespan Respite Conference in Buffalo, NY. See their PPT Presentation, Creating a Culture of Evidence-Based Respite Care Through an International Knowledge Exchange.

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

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 contact Ray Kirk at ARCH if you have any questions.