Advancing Respite by Building Bridges among Respite Researchers

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Overview of ARCH’s Respite Research Initiative

Committee for the Advancement of Respite Research (CARR)
The ARCH National Respite Network and Resource Center

Training and Technical Assistance Division provides support to State Respite Coalitions, service providers and families through consultation, training, evaluation, and research (archrespite.org);

National Respite Locator Service (NRLS) helps family caregivers and professionals locate respite services and funding sources in their communities (archrespite.org/respitelocator);

National Respite Coalition is the policy and advocacy division of ARCH (archrespite.org/national-respite-coalition); and

Lifespan Respite Technical Assistance and Resource Center, funded by the U.S. Administration for Community Living, supports State Lifespan Respite grantees and their partners in developing state respite systems serving caregivers of persons of all ages and conditions (archrespite.org/ta-center-for-respite).
ARCH Goals for Advancing Respite Research

- Improve access to and quality of respite services
- Identify aspects of respite services and models that make them exemplary
- Evaluate and replicate promising respite services
- Translate research findings into practice and policy
- Identify additional possibilities (e.g., funding opportunities for research)
Why is research important to the future of respite?

- Model Development and CQI
- Efficacy Testing & Outcome Evaluation
- Building the Evidence Base for Respite Care
- Improving Lives and Well-Being (QOL)
- Advocacy and Funding
Explore in-depth the current status of respite research

Propose strategies to overcome barriers to research

Develop a plan to encourage rigorous research in key areas that will translate to meaningful strategies and approaches to care.
An Inclusive Definition of Respite*

“Respite is planned or emergency services that provide a caregiver of a child or adult with a special need some time away from caregiver responsibilities for that child or adult, and which result in some measurable improvement in the well-being of the caregiver, care recipient, and/or family system”

(Kirk & Kagan, 2015)

*Pre-pandemic
Recommendations for Future Research

(Kirk & Kagan, 2015)
Purpose – To help implement the Expert Panel’s research recommendations

Identified more than 30 foundations and government research programs with potential interest in funding respite research.

Continue to identify and compile a list of academic scholars and other researchers to connect with the funding sources in a coordinated, collaborative research program.
Annotated Bibliography of Respite and Crisis Care Studies, 5th Edition

2020

ARCH National Respite Network and Resource Center
Summit Report
Research Considerations

Model definition: Describing the respite model under investigation

Research funding

Measures and measurement

Culturally appropriate research with hard-to-reach populations

Rethinking cost-effectiveness and cost/benefit studies

Workforce development and access to respite

Utilizing research findings to inform and improve policy and practice

Impact of COVID-19 on respite and post-pandemic respite
Committee for Advancement of Respite Research (CARR)

- Charged with leading the next phase of ARCH's work in building an evidence-base for respite
- Considered the findings from the Respite Research Summit
Prioritized for Future Investigation

1. Define and measure the **VALUE** (cost-effectiveness) of respite

2. Recommend common data elements (**CDE**) for respite-related research

3. Expand **CULTURALLY** appropriate research with hard-to-reach or -serve populations

4. Understand the impact of the **COVID-19** pandemic on respite and evaluate the impact of new and modified respite interventions on the wellbeing of family caregivers.
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Lifespan Respite Technical Assistance Center
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