

Advancing Respite by Building Bridges among Respite Researchers

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Session Overview

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

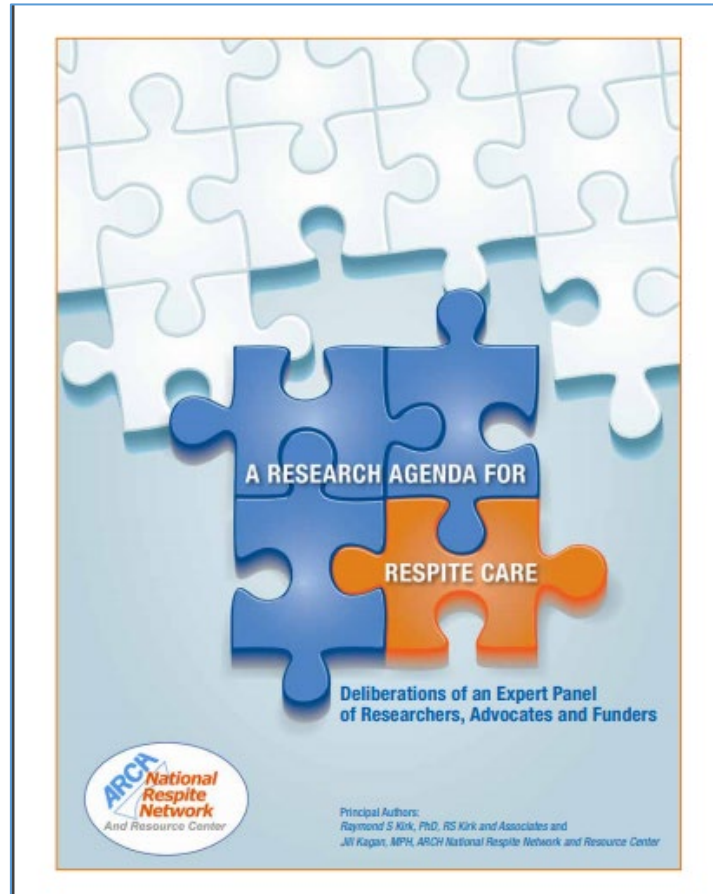


IMPROVING
LIVES AND WELL-
BEING (QOL)



ADVOCACY AND
FUNDING

ARCH Expert Panel on Respite Research



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.

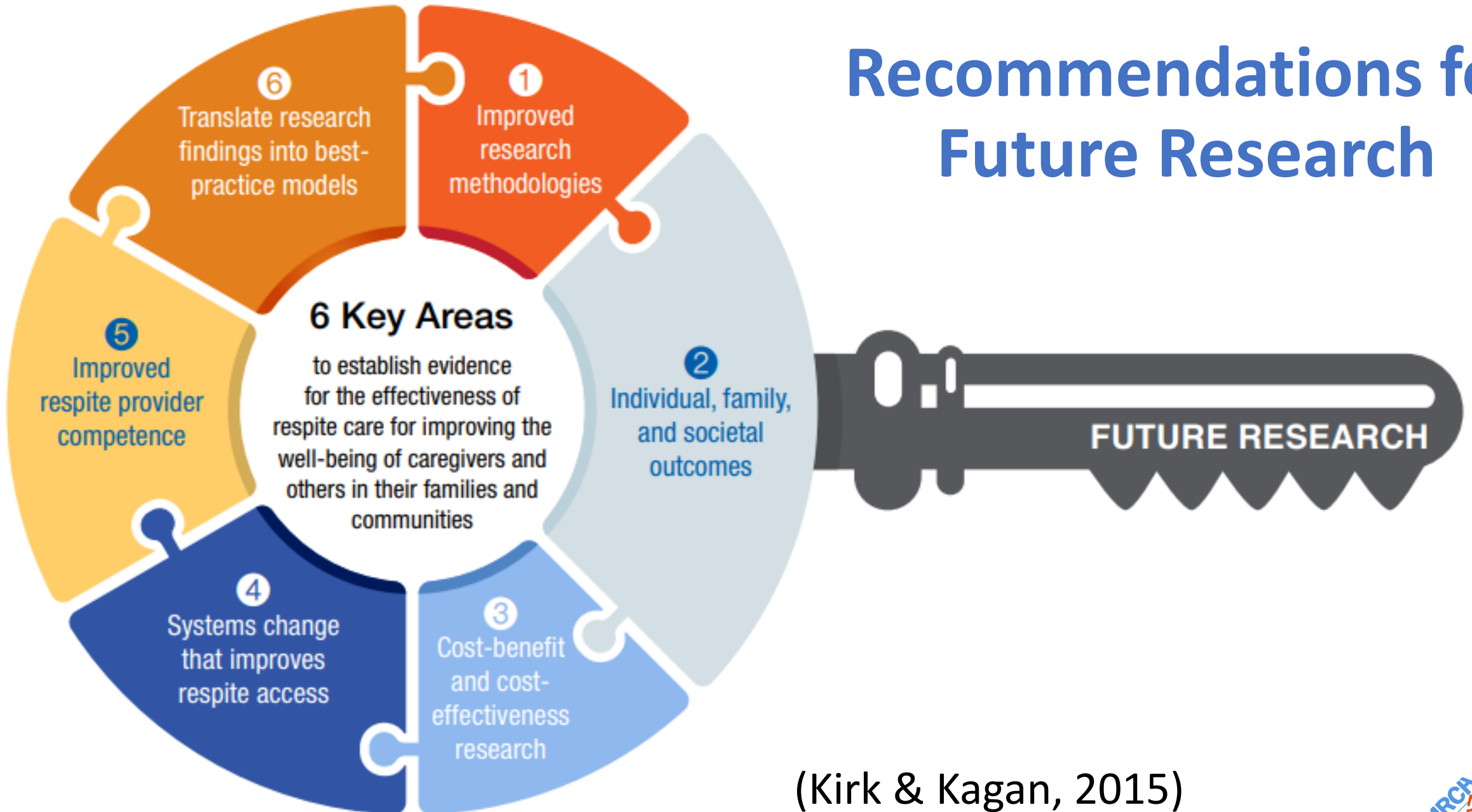
An Inclusive Definition of Respite*

“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)



Research Consortium

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**

Annotated Bibliography of Respite and Crisis Care Studies, 5th Edition

ARCH VIRTUAL RESPITE
RESEARCH SUMMIT
SEPTEMBER 29 AND 30, 2020



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

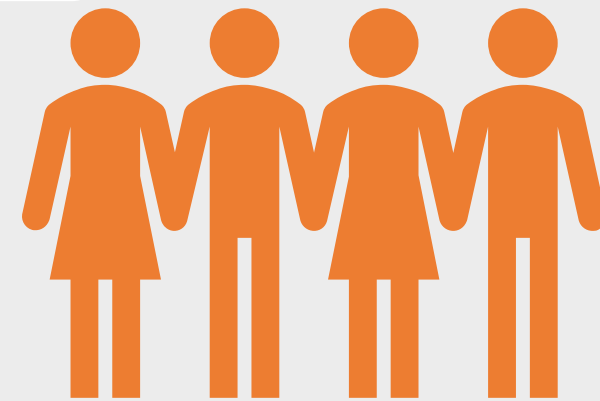
Workforce development and access to respite

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



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



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



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



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.



CONTACT INFORMATION

archrespite.org/respite-research

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Lifespan Respite Technical Assistance Center

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