

Data Collection Efforts Within Adult Day, Respite Care, and Home Care Services

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ARCH
National Respite Network
AND RESOURCE CENTER

Overview

- Overview of ARCH's Respite Research Initiative
- Committee for Advancement of Respite Research (CARR)
- Current Data Collection Efforts
- Alignment with the 2022 National Strategy to Support Family Caregivers

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

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).

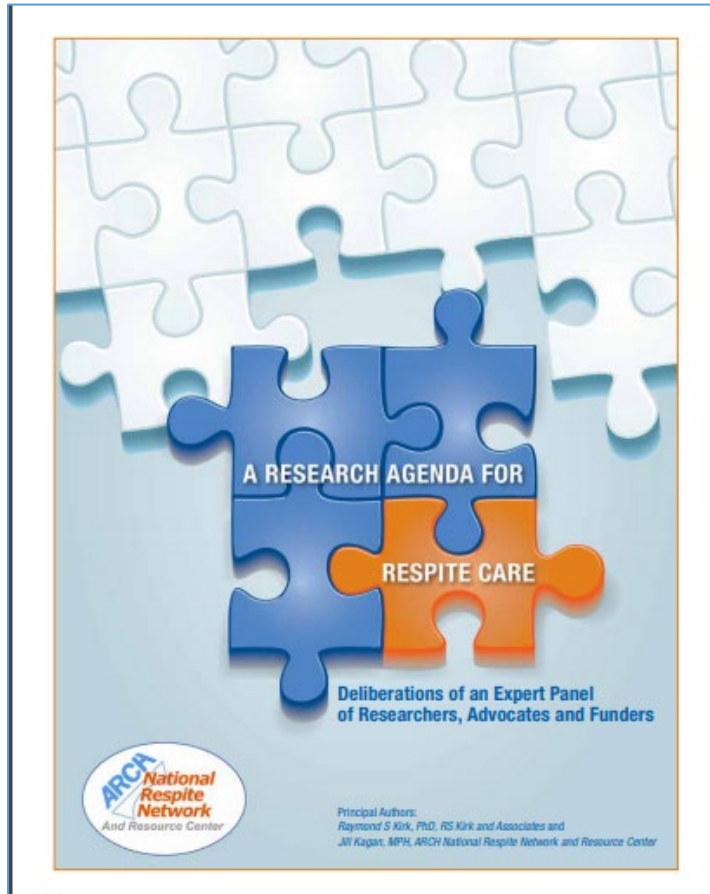


ARCH Goals for Advancing Respite Research

- 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)



ARCH Expert Panel on Respite Research

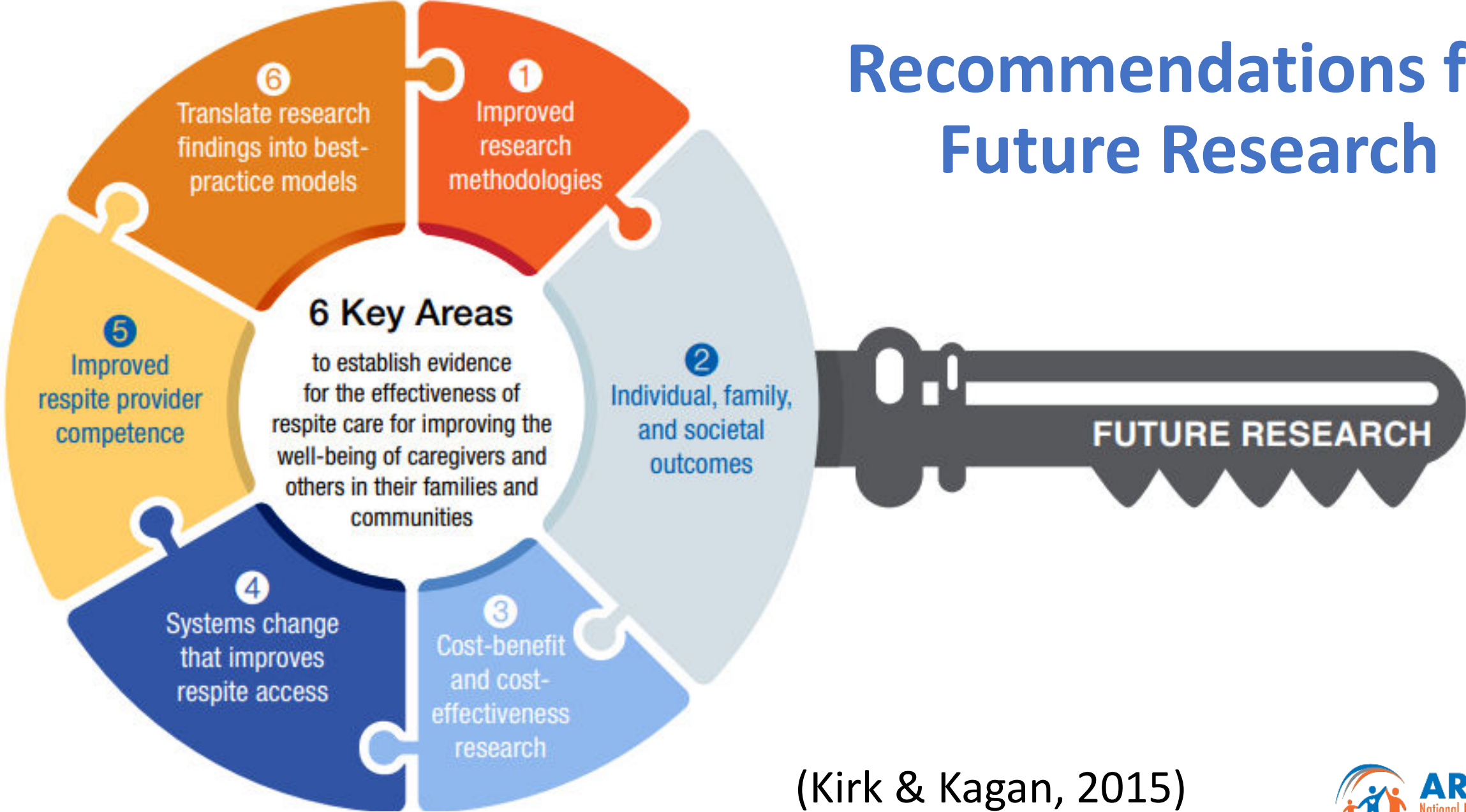


Explore in-depth the current status of respite research

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.

Recommendations for Future Research



(Kirk & Kagan, 2015)





Annotated Bibliography
of Respite and Crisis Care
Studies, 6th Edition

2022

ARCH National Respite Network
and Resource Center

**Annotated
Bibliography of
Respite and Crisis
Care Studies
*6th Edition***

2020 Respite Research Summit 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)

- Advises ARCH on the execution of its respite research initiative
- Comprised of former members of the Expert Panel on Respite Research, research scholars and evaluators, and foundation representatives



CARR Work Groups



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



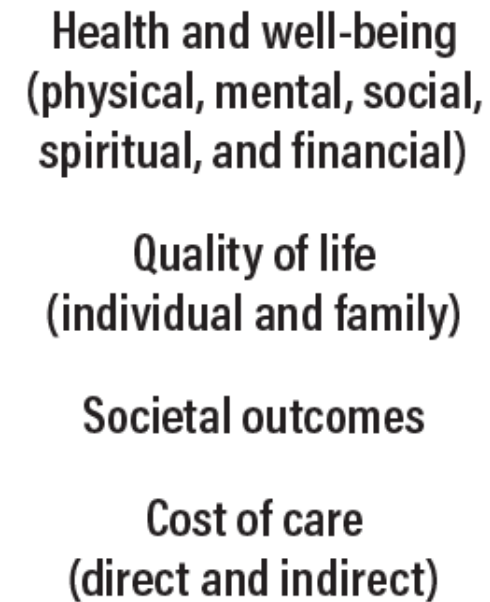
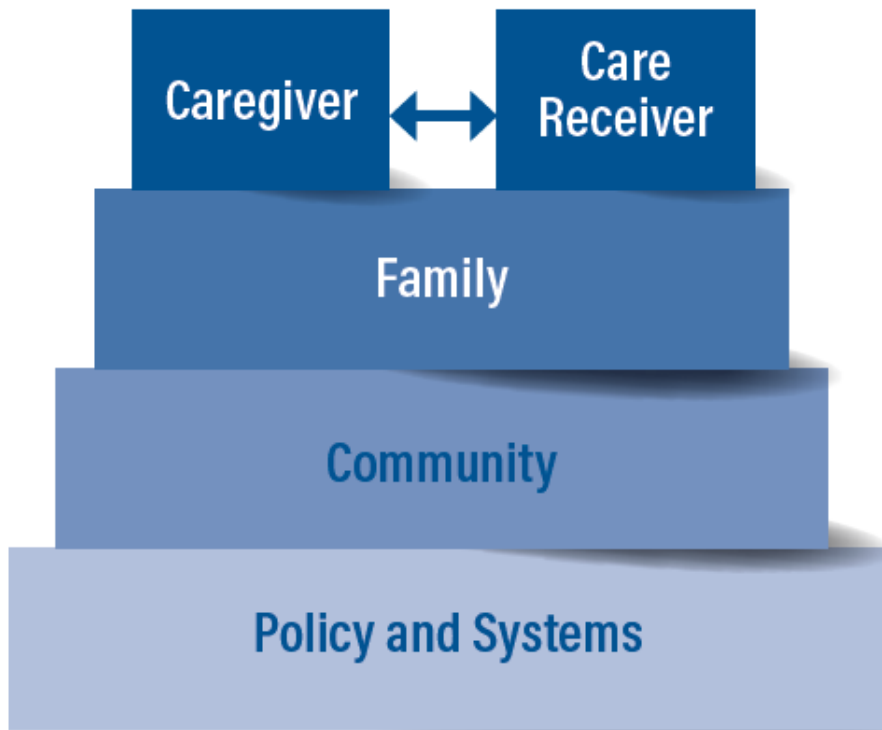
Recommend common data elements (**CDE**) for respite-related research



Expand **CULTURALLY** appropriate research with historically underrepresented populations

Products

- Measuring the Value of Respite
- Recommended Common Data Elements (CDEs) for Respite-related Research
- Resources for Culturally and Linguistically Competent Respite Research
- Ensuring Cultural and Linguistic Competence: A Guide for Respite Researchers
- Learn more at archrespite.org/research

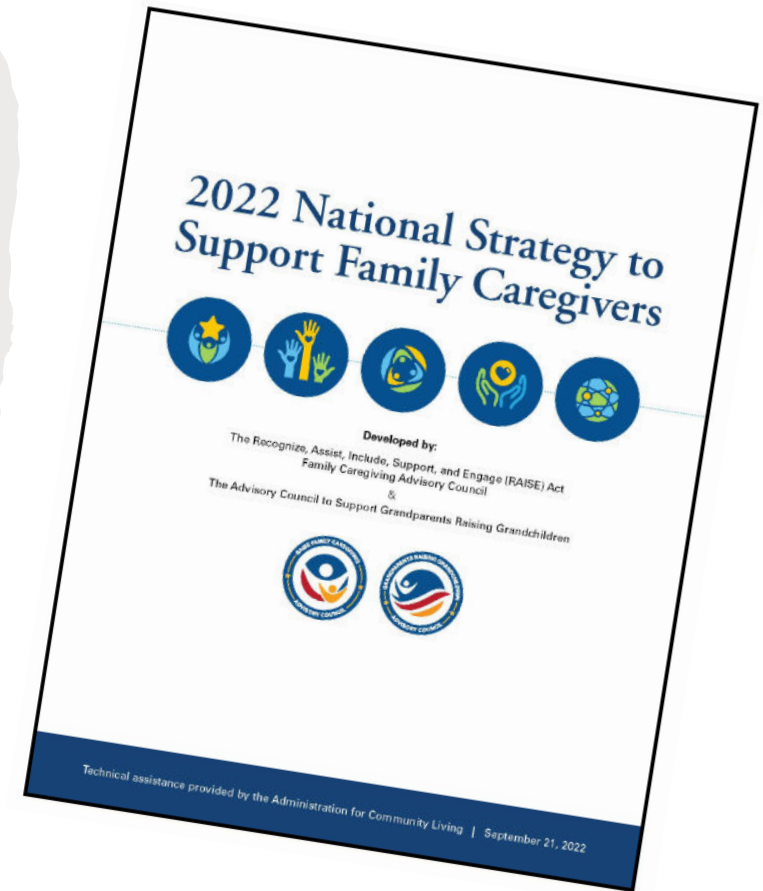


Context Varies and Changes Over Time and Across the Life Course

The Value of Respite Model

Alignment with the 2022 National Strategy to Support Family Caregiving

- Goal 5: Expand data, research, and evidence-based practices to support family caregivers
- CARR Work Groups Crosswalk
- National Alliance for Caregiving CARE Agenda





2024 National Lifespan Respite Conference

MAY 21-23 . ALBANY, NY



RAISE the Bar for

Respite

Strategies to strengthen family caregivers

2024 National Lifespan Respite Conference ✦ May 21-23, 2024 • Albany, NY

Respite Research Consortium

- **CONNECTS** interested researchers and funders to engage in respite research that will strengthen the evidence base for respite services
- Get **UPDATES** on new research studies, current literature reviews, data sources, funding opportunities, upcoming events and new report releases
- **SHARE** information about your respite research study on the ARCH website in order to recruit family caregivers, respite providers or other study participants
- **SUBSCRIBE** at archrespite.org/research/respite-research-consortium/#Subscribe

Join the BREAK Exchange



- International group of researchers, respite providers, agencies, and individuals who are committed to building a culture of evidence-based respite care
- Currently, there are more than 292 members from 18 countries in the Exchange!
- Follow the BREAK Exchange on Social Media
- Visit our website, join the email list, and complete your member profile at **breakexchange.org**
- Email us at info@BREAKexchange.org





CONTACT INFORMATION

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Lifespan Respite Technical Assistance Center

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