



Creating a culture of
evidence-based
respite care through
an international
Knowledge
Exchange

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Workshop Overview

❖ Background

- Respite Research
- Evidence Based Practice
- Practice Based Evidence
- Knowledge Exchange

❖ Speed networking activity

❖ Building a Knowledge Exchange activity

❖ How to stay connected

RESPITE RESEARCH

Caregiving Research is Abundant

- ❖ Increased Stress (Estes, 2009)
- ❖ Increased Fatigue (Whitmore, *in development*)
- ❖ Poorer Quality of Life (Vasilopoulou & Nisbet, 2016)
- ❖ Marital Stress → Divorce (Saini et al., 2015)
- ❖ Financial Stress and Job Loss (Lindley, Chavez & Zuckerman, 2016)
- ❖ Abuse/Neglect (Cowen & Reed, 2002)

Respite Care Research is Limited

- ❖ Respite care may decrease stress and other negative outcomes (Harper et al., 2013; Whitmore, 2016b; Whitmore & Snethen, In Press)
- ❖ Respite care needs are largely unmet (Farmer et al., 2014; Nageswaran, 2009; Whitmore & Snethen, 2018)
- ❖ Respite care is based primarily on “practical ideas and good intentions” (Kirk & Kagan, 2015)



Why Research Respite Care?

- ❖ Understand and develop model practices
- ❖ Continuous quality improvement of existing services
- ❖ Build the evidence base for respite care
- ❖ Improve the lives and well-being of caregivers and care recipients
- ❖ Advocacy
- ❖ Funding

**Slide content adapted from Raymond Kirk*

A RESEARCH AGENDA FOR RESPITE CARE

*Deliberations of an Expert
Panel of Researchers,
Advocates and Funders*

(Kirk & Kagan, 2015)

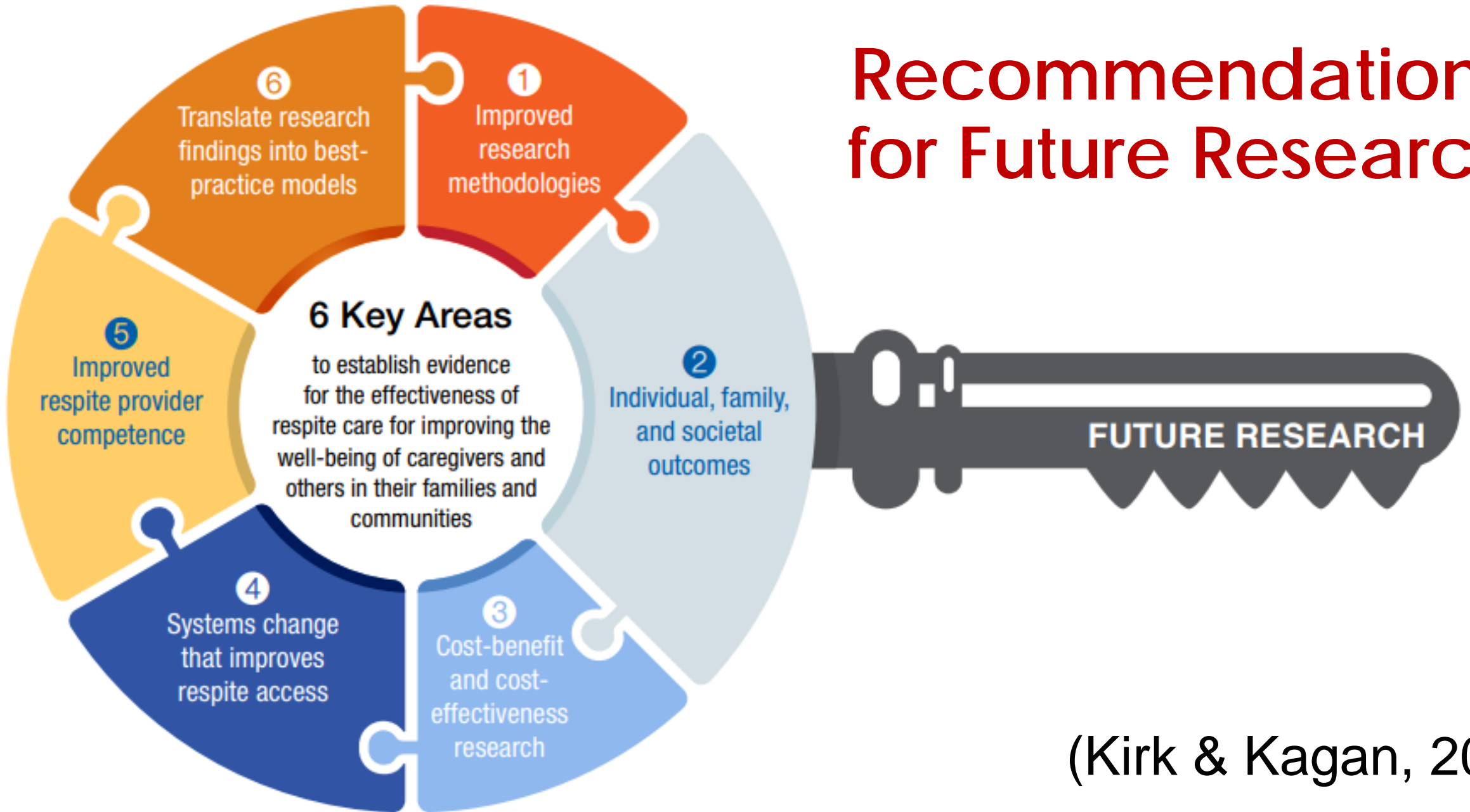


https://archrespice.org/images/docs/2015_Reports/ARCH_Respice_Research_Report_web.pdf

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)

Recommendations for Future Research



(Kirk & Kagan, 2015)

Six Key Areas

- 1) Address foundational methodological concerns
- 2) Research individual, family, and societal outcomes
- 3) Conduct appropriate cost-benefit and cost/effectiveness research
- 4) Research systems change that improves respite access
- 5) Research improving respite provider competence
- 6) Conduct translational research that informs respite policy and practice

**Slide content adapted from Raymond Kirk*

Research Consortium

- ❖ Identified more than 30 foundations and government research programs with potential interest in funding respite research. Actively communicating with them at this time.
- ❖ Working to identify and compile a list of academic scholars and other researchers to connect with the funding sources in a coordinated, collaborative research program.

UK Short Breaks Research & Practice Development Group

- ❖ Support the building of research/practice partnerships to deliver nationally and internationally excellent work that makes a positive difference to the everyday lives of carers and people with complex support needs
- ❖ Facilitate knowledge exchange between academia, policy and practice in ways that encourage innovations in policy and practice development





Practice-Based Evidence

Knowledge gained over time
through experience.

KNOWLEDGE EXCHANGE

Defining Knowledge Exchange

What is an international Knowledge Exchange focusing on respite?

- ❖ an innovative method for identifying best respite care practices that can be replicated - adapted and applied in different communities and cultural contexts

Why a Knowledge Exchange?

- ❖ to build a culture of best practices and evidence-based respite care so that, in the future, respite care services will be intentionally structured to maximize impact (ex. Respite services that reduce social isolation and increase social belonging among the families they serve - families of children with special healthcare needs (CSHCN)).



Knowledge Exchange – key elements

- ❖ Creates a “two-way flow of people and ideas between the research environment and wider economy, thereby contributing to national prosperity, the quality of life of citizens, and cultural enrichment of our society.”*
- ❖ Facilitates and supports an interdisciplinary and cross-sector team of researchers and respite program staff.
- ❖ Provides a forum for:
 - open scholarship among partners;
 - infrastructure for collaborative research and timely exchange of content review and decision-making; and
 - close working relationships and coordinated strategies to build strong networks within national and international respite/short break systems.
- ❖ Builds a knowledge base of best practices.

Developing a KE – proposed action plan

- ❖ Identify best practices in respite care that have potential to be replicated -- adapted, implemented and evaluated.
- ❖ Establish an Advisory Board
 - includes caregivers and other key stakeholders to provide consultation and guidance.
 - focused on maximizing stakeholder engagement in replication and evaluation and ensuring that practices are not only effective, but are also seen as socially relevant and culturally sensitive.

Leveraging Existing Infrastructures –

ex. ARCH National Respite Network in the U.S. and others

- ❖ Provide ongoing technical assistance to pilot sites for implementation.
- ❖ Support local community advisory boards to guide the adaptation of best practices to local cultural and political contexts.
- ❖ Provide ongoing evaluation support to ensure both process and outcome measures.
- ❖ Issue mini-grants through a request for proposals (RFP) to identify pilot sites that will adapt, implement and evaluate best practices.

Challenges and Opportunities

- ❖ When applying best practices from around the world, it will be critical to adapt to cultural differences to cultivate the trust necessary for caregivers to accept respite care.
- ❖ These differences will be identified through the Knowledge Exchange process and in consultation with the community advisory board, which will include caregivers and other stakeholders.
- ❖ It will also be important to leverage existing infrastructure to support sustainability of new practices. (ex. The robust national network of ARCH-supported State Respite Coalitions is a pillar for support and sustainability.)

**SPEED
NETWORKING
ACTIVITY**

Sharing Best Respite Practices

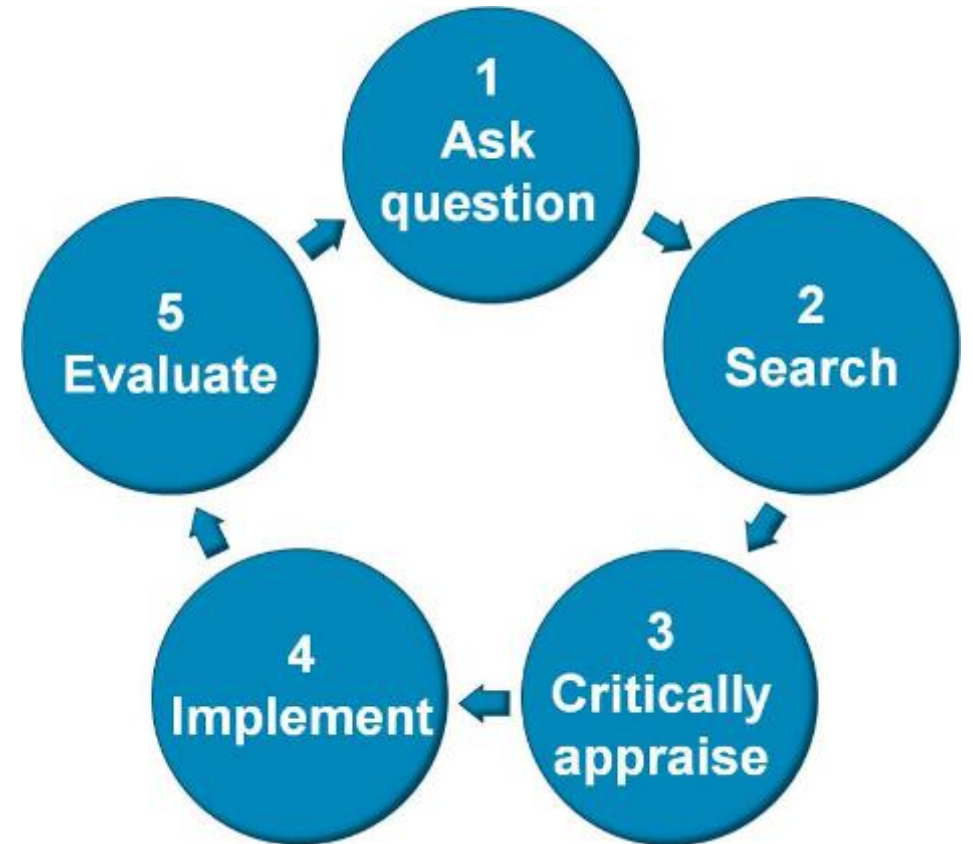
- ❖ Guidelines – 10 minutes total (1 minute each person)
- ❖ Share your name, location, organization, and type of work you do.
- ❖ Share your best respite care practices – choose 1 to share and brag (Be sure to say why you consider it a “best practice”).

Ready...Set... GO!!!

**BUILDING A
KNOWLEDGE
EXCHANGE
ACTIVITY**

Building a culture of evidence-based respite care

- ❖ Partner with academic researchers or evaluator
- ❖ Identify projects/questions
- ❖ Define potential measures
- ❖ Advocate for research funding
- ❖ Disseminate findings
- ❖ Translate to practice



How could an international knowledge exchange be structured to best support you?

- 1 minute alone
- 2 minutes in pairs
- 4 minutes as a table
- 8 minutes as large group



**Adapted version of the 1-2-4-All Activity from
www.liberatingstructures.com*

HOW TO STAY CONNECTED

The BREAK (Building Respite Evidence And Knowledge) Exchange



- Join our Facebook Group “The BREAK Exchange”
- Sign up on the listserv
- Attend ISBA 2020!

YOU CAN'T POUR FROM AN EMPTY CUP.

TAKE CARE OF YOURSELF FIRST.

- CHINESE PROVERB