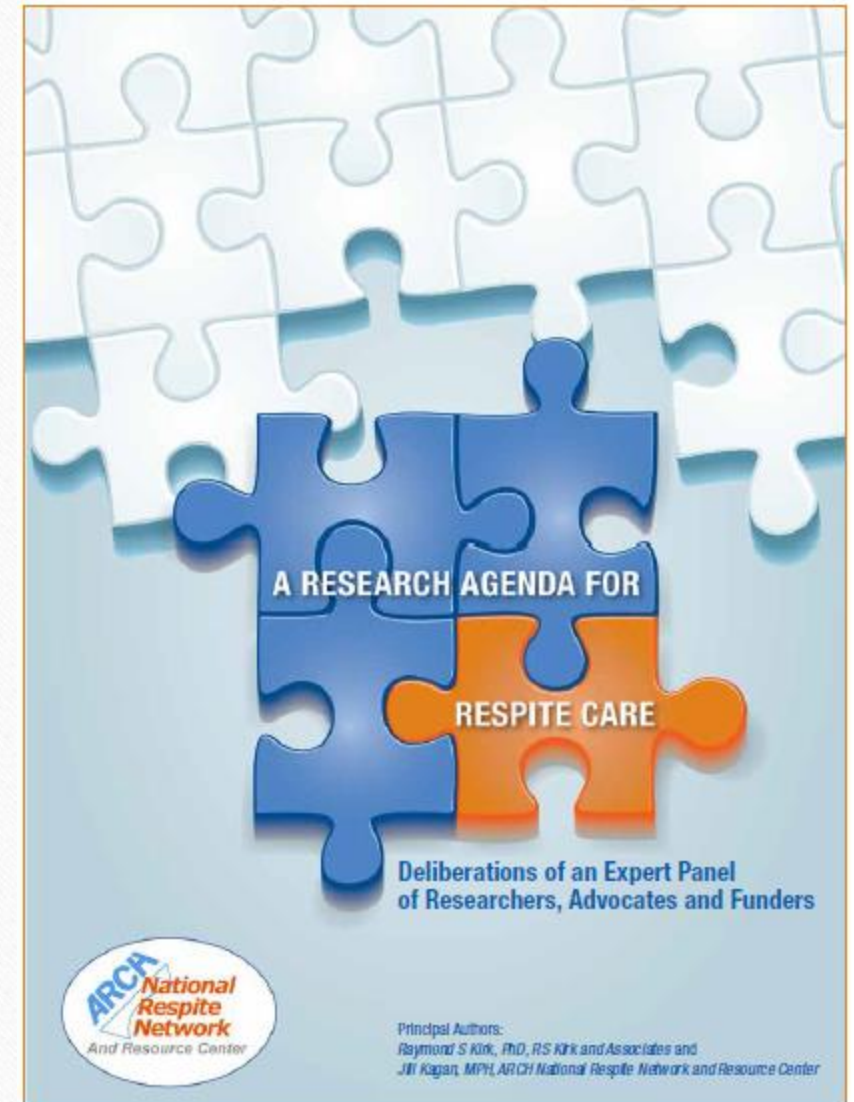


A RESEARCH AGENDA FOR RESPITE CARE

Deliberations of an Expert Panel of
Researchers, Advocates and Funders

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**Presented by Susan Summers, PhD and
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Why an Expert Research Panel?

- Literature Review 2012/2013
- Annotated Bibliography 2014, ongoing
 - Lack of clarity about intended recipient of respite
 - Lack of model clarity/categorization
 - Lack of focus on outcomes
 - Lack of efficacy testing or even outcome evaluation

Why is research important to the future of respite?

- Model Development
- Continuous Quality Improvement of Existing Services
- Efficacy Testing/Outcome Evaluation
- Building the Evidence Base for Respite Care
- Improving Lives & Well-Being of Caregivers & Care Recipients
- Advocacy and Funding

The Expert Panel and the Process

- 14 volunteer researchers, advocates and funders
- 6 meetings over 18 months (2013 – 2014, conference calls and face-to-face meetings)
 - Explore in-depth the current status of respite research.
 - Propose strategies to overcome barriers to research.
 - Develop a plan to encourage rigorous research and translate research to meaningful strategies for respite care.

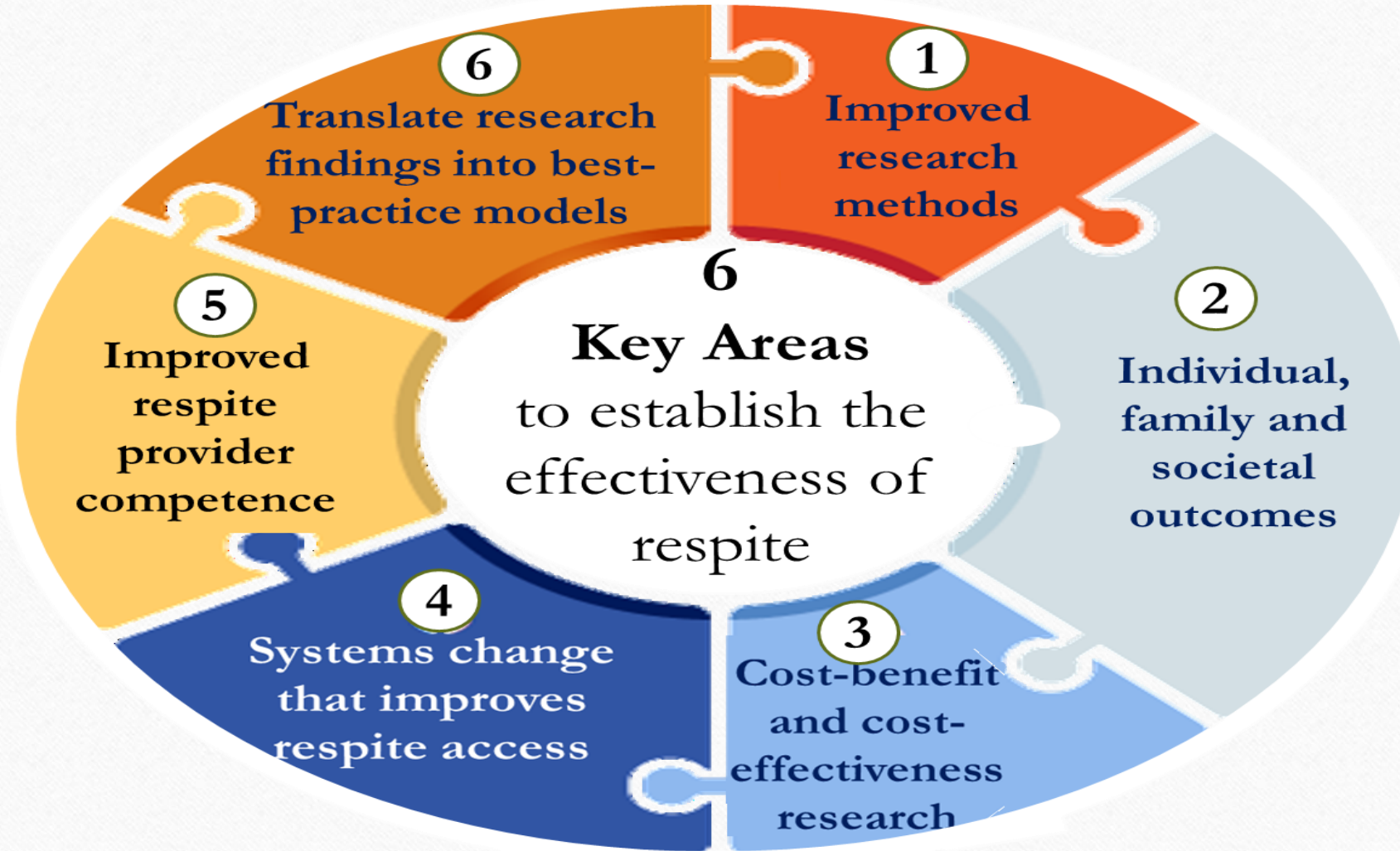
Seven Goals of the Panel (1)

- 1. Craft a respite definition and framework for guiding the development of the research agenda;
- 2. Identify the current status of respite research broadly, including research gaps and limitations, taxonomical approaches used by past and current research on respite, methodological concerns and issues, and barriers to respite-focused research;
- 3. Identify areas of research to focus the recommendations (e.g. family caregiver and/or care recipient outcomes; service satisfaction; economic impacts; improving service delivery & access);

Seven Goals of the Panel (2)

- 4. Identify methodological approaches and other strategies to address identified barriers to respite research;
- 5. Identify incentives to engage researchers in the respite research agenda developed by the panel;
- 6. Identify and encourage funders to support implementation of respite research recommendations promulgated by the panel; and
- 7. Identify strategies for supporting translation of these goals for use in practice settings.

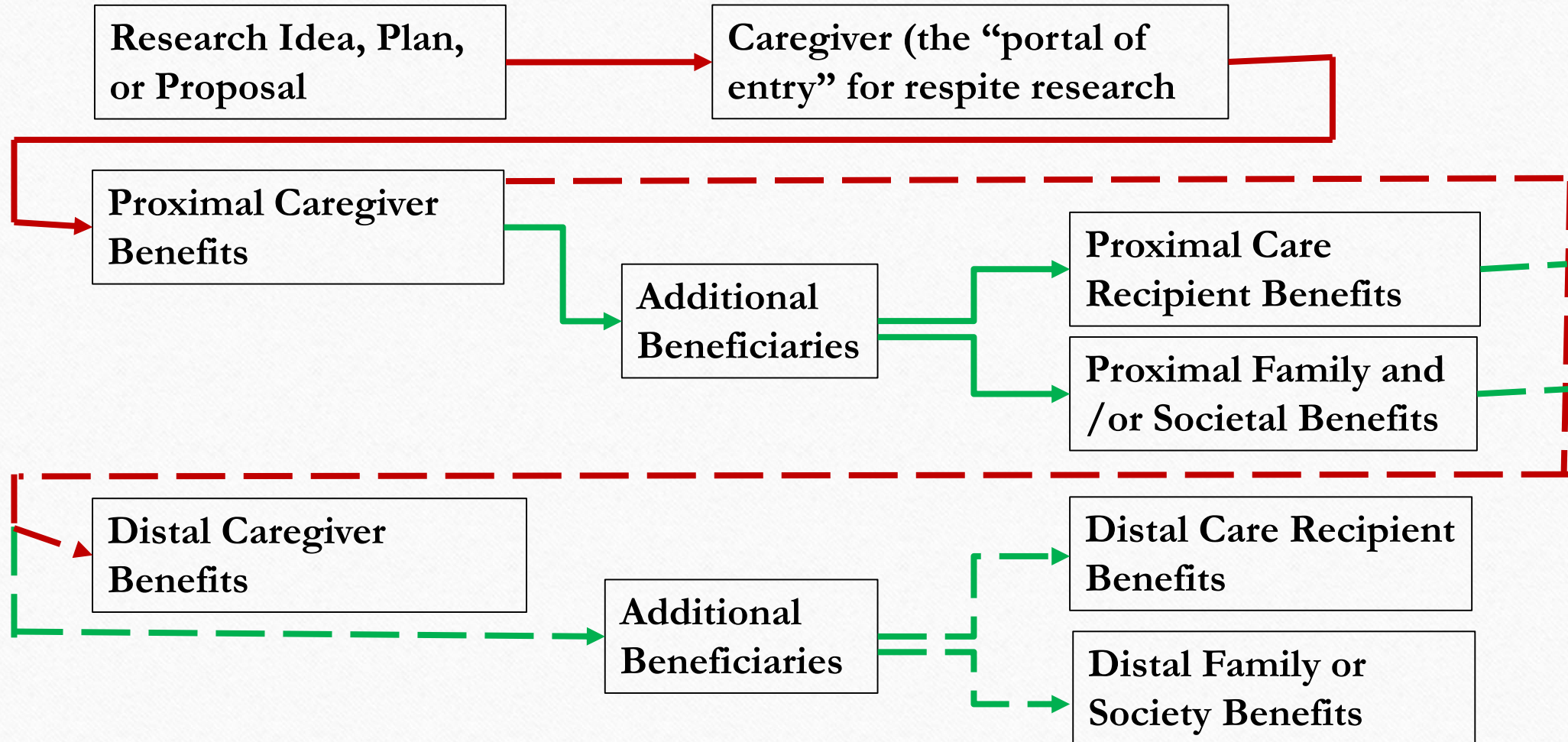
RECOMMENDATIONS



An Inclusive Definition of Respite

Respite is the planned or emergency provision of 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.

Research Flow Schematic



The Research Focus on Outcomes

- **Proximal outcomes for caregivers, care recipients and others**
 - Outcomes that might be observable during or immediately after a spell of respite, such as relief from depression
- **Distal outcomes for caregivers, care recipients and others**
 - Outcomes that might take time to emerge or to be measured, such as delayed or avoided institutional care, or family continuity
- **Societal outcomes**
 - Outcomes that benefit society, generally, such as cost-effectiveness, cost/benefit, employment

The Panel's Outcomes Schema: Proximal and Distal Outcomes for Targets of Respite

Individual & Family-Level

- **Family Relationships**
- **Social Relationships**
- **Health & Mental Health Effects**
- **Living Status**
- **Quality of Life**
- **Experience of Care**
- **Community Participation**

Societal Level

- **Cost-Effectiveness & Cost/Benefit**
- **Employment**

E.g., Family Relationship Proximal Outcomes

- quality of marital/partner relationships.
- perceived strength of relationships.
- relationships with other family members.
- relationship with care receiver.
- time available for non-care receiving family members.
- reduced risk of care receiver maltreatment.
- positive attitude towards care receiver.
- families' ability to utilize social support.

E.g., Family Relationship Distal Outcomes

- family continuity
- relationship stability (separation/divorce)
- family vacations, outings, events with or without care receiver
- reduced incidence of care receiver maltreatment
- long-term increase in family's social capital

Outcome Category	Proximal Outcomes (results of direct service)	Distal Outcomes (changes in well-being over time, following respite)
Individual and Family Level Outcomes		
Family Relationships	<ul style="list-style-type: none"> • quality of marital/partner relationship • perceived strength of relationships • relationship with other family members • relationship with care receiver • time available for non-care receiving family members • reduced risk of care receiver maltreatment • caregiver's positive attitude towards care receiver and other family members • care receiver's positive attitude towards care receiver and other family members • family's ability to develop and utilize social networks 	<ul style="list-style-type: none"> • family continuity • relationship stability (separation and divorce) • family vacations, outings, events with or without care receiver • reduced incidence of care receiver maltreatment • long-term increase in family's social capital
Social Relationships (outside the family)	<ul style="list-style-type: none"> • frequency/duration/quality of social interactions (both caregiver and receiver) • maintenance of friendships (both caregiver and receiver) • accessing/utilizing support groups • family's ability to organize and utilize social support/social capital 	<ul style="list-style-type: none"> • caregiver's sustained willingness to provide care • caregiver's sustained confidence and ability to provide care • long-term increase in family's use of social capital

Concluding the Initial Work of the Panel

- Early fall of 2015 the Respite Network & Resource Center submitted the Panel's Final Project Report.
- Final Project Report was published in October 2015.

http://www.nasdds.org/uploads/documents/ARCH_Respite_Research_Report_web.pdf

- The Resource Center received approval to attempt to establish a consortium of public and private funders to collaborate on a focused plan for respite research.

Current and Future Endeavors

- 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.
- Promote adoption of the Panel's definition of respite, research schema and flow diagram, taxonomy of terms, research methods and outcomes from the Project Final Report.

Thank you for your attention!

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