

A RESEARCH AGENDA FOR RESPITE CARE
Deliberations of an Expert Panel of
Researchers, Advocates and Funders

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

The Expert Panel and the Process

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

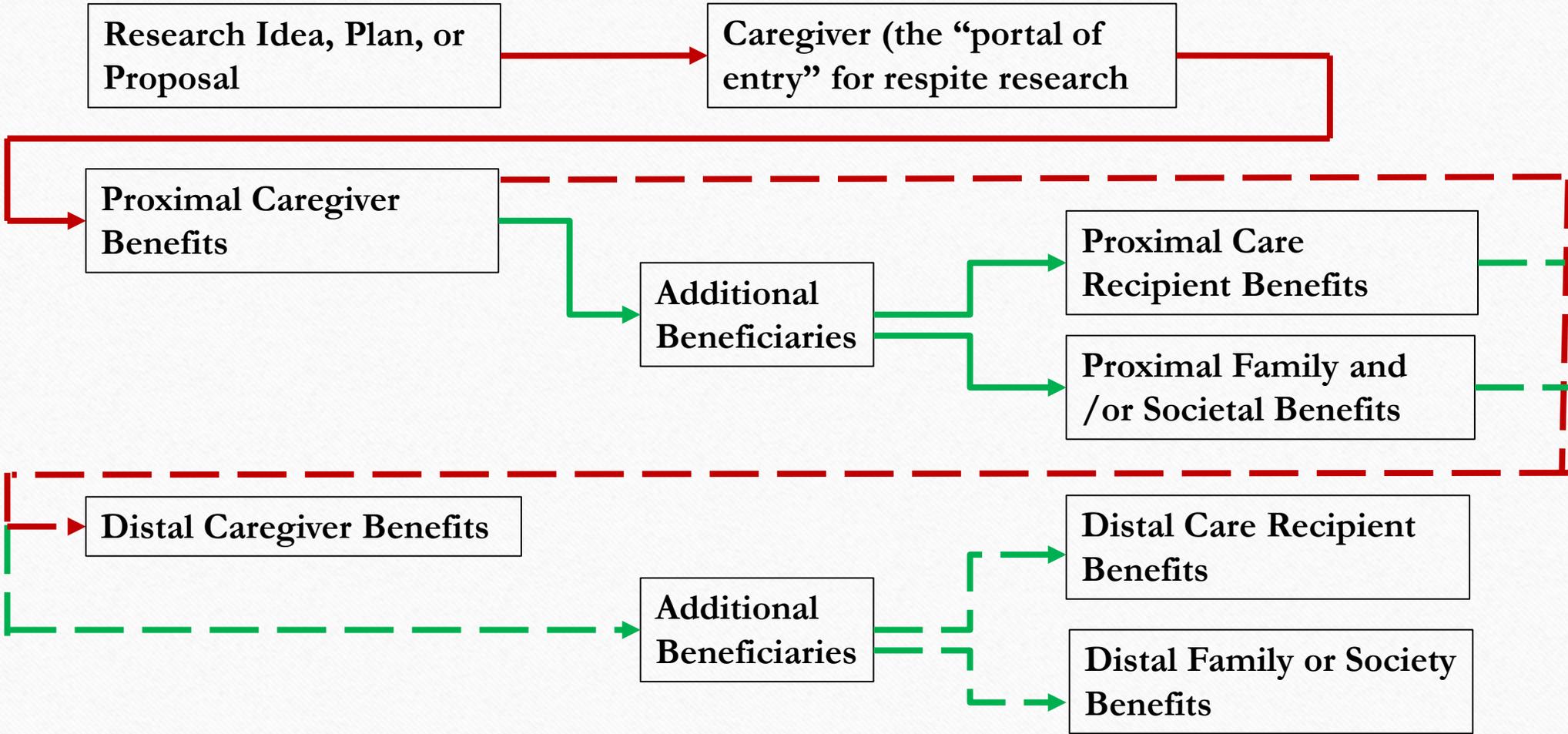
Panel Goals

- Identify the current status of respite research: research gaps / limitations, taxonomical approaches, methodological issues, and barriers to respite-focused research;
- Craft a respite definition and framework for guiding the development of the research agenda
- Identify areas of respite research on which to focus the recommendations
- Identify methodological approaches and strategies to address barriers to respite research
- Identify strategies for supporting translation of these goals for use in practice settings
- Identify incentives to engage researchers in the respite research agenda developed by the panel
- Identify and encourage funders to support implementation of respite research recommendations promulgated by the panel.

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 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 Outcome Categories

- **Family Relationships**
- **Social Relationships (outside the family)**
- **Health and Mental Health Effects**
- **Living Status**
- **Quality of Life**
- **Experience of Care (perceptions of caregivers and care receivers)**
- **Community Participation and Involvement**
- **Cost Effectiveness and Cost/Benefit**
- **Employment**

The Panel's Recommendation Categories

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

Future Endeavors

- **Submit the Panel's Final Project Report to the AoA for final review and sign off**
- **Promulgate the Final Project Report, generally**
- **Endeavor to establish a consortium of public and private funders to collaborate on a focused plan for respite research**

Thank you, and stay tuned!