



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 (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 respite research on which to focus the recommendations (e.g. family caregiver and/or care recipient outcomes; service satisfaction; economic impacts; improving service delivery and access, etc)

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.

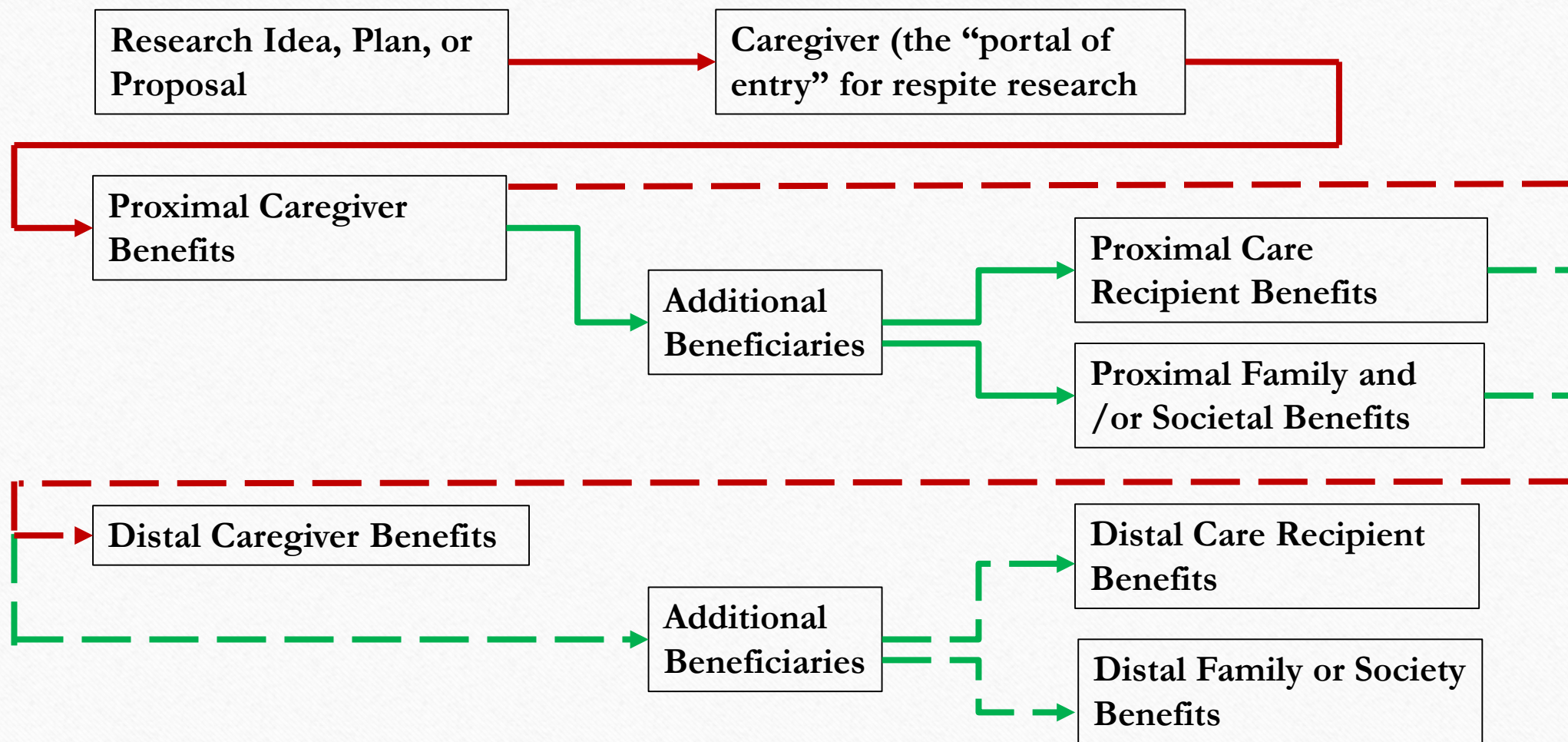
The Panel's Recommendation Categories

- **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**

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 Outcomes**
 - Family Relationships
 - Social Relationships
 - Health and Mental Health Effects
 - Living Status
 - Quality of Life
 - Experience of Care
 - Community Participation
- **Societal Level Outcomes**
 - Employment
 - Cost-Effectiveness and Cost/Benefit

E.g., Family Relationship Outcomes

- **Proximal outcomes**

- quality of marital/partner relationships
- 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
- positive attitude towards care receiver
- families ability to utilize social support

- **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

Concluding the Initial Work of the Panel

- **Early fall of 2015 the Respite Network and Resource Center submitted the Panel's Final Project Report to the Administration on Community Living for final review and acceptance.**
- **Final Project Report was published in October 2015**
- **http://www.nasddd.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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