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

- Research Idea, Plan, or Proposal
- Caregiver (the “portal of entry” for respite research)
- Proximal Caregiver Benefits
- Additional Beneficiaries
- Proximal Care Recipient Benefits
- Proximal Family and/or Societal Benefits
- Distal Caregiver Benefits
- Additional Beneficiaries
- Distal Care Recipient Benefits
- Distal Family or Society Benefits
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!