

Roundtable Discussion Guide

Group 3: Research systems change that improves respite access

Overview of the Key Recommendation

During their review of existing research, the Panel recognized that an examination of the efficacy of the existing respite system—which includes a large variety of service models, and a large number of caregivers and care receivers who could potentially benefit from respite— must include large numbers of varied and culturally diverse caregivers receiving respite. At the same time, the Panel recognized that there are also large numbers of caregivers who might benefit from respite, but for whom respite is not available or accessible due to a number of reasons occurring across systems levels—such as lack of funding, lack of awareness of the service, limited understanding of how and where to access services and funding, and unavailability of services or trained providers or volunteers. The Panel therefore recommends studies occurring at multiple systems levels.

Overarching question

What is needed to advance respite-related systems research?

Equity lens reminder

In our discussion, consider how we can ensure respite-related systems research represents the broad diversity of family caregivers and care-receivers across the lifespan.

Question 1

If resources were not an issue, what are the respite-related systems research/evaluation questions that you would want answered? Consider:

- What are the various systems and issues that impact respite access?
- If you work with a respite program, what questions or concerns do you have about existing respite systems or models? How do respite systems influence your program's work? What's working/not working?
- If you are a researcher, what research design and methods would you use to conduct studies at multiple systems levels?
- Are there questions you would want answered related to a specific racial or ethnic group or other under-represented group? Do certain groups face unique systems-related challenges to accessing respite?
- How should we measure these systems issues? Do you have any recommended survey tools or instruments we should consider?

Question 2

What are the major barriers to conducting high quality respite-related systems research and how can we work together to overcome them?

- What are the barriers to conducting systems research that represents the broad diversity of family caregivers and care-receivers? Consider specific racial and ethnic groups or other underrepresented groups you work with.
- How can we overcome recruitment and retention barriers for family caregivers?
- How can we overcome funding barriers for respite-related systems research?

Question 3

How can we make respite-related systems research more relatable and transferrable to respite practice?

- What methods of dissemination should we consider? What is the best way to share research findings with practice partners, funders, and policymakers?
- What are effective strategies for engaging respite providers, family caregivers, and care-receivers in the research process?

Summary

We now want to take a few minutes to reflect on the overall conversation. Consider the following questions:

- What key themes did you notice?
- What stood out to you as key ideas from our conversation?
- What questions do you still have?
- What do you feel is the most important thing we can do to advance respite-related systems research and improve respite access?