RECOMMENDATIONS FOR FUTURE RESEARCH

The Panel’s foundational work, including crafting a proposed respite definition and research framework, guided the development of specific and practical recommendations in the following six categories:

1) **Address foundational methodological concerns.** From their review of the literature, the Panel ascertained the methodological shortcomings that have hampered current respite research. To address these issues, the Panel made specific recommendations to address these shortcomings from the perspectives of research design, construction of independent and dependent variables relating to respite services, and methods and statistical analyses.

2) **Research individual, family, and societal outcomes.** The Panel identified the family caregiver as the “portal of entry” for future respite research, and set the expectation that at least one outcome relating to caregiver well-being and quality of life be measured during any research study. However, the Panel specified that a focus on family caregiver outcomes does not negate the need to study additional outcomes. Recommendations reflect the Panel’s recognition of benefits that may also accrue from respite to the care receiver, the family system, and society, and are therefore appropriate for inclusion in research studies.

3) **Conduct appropriate cost-benefit and cost-effectiveness research.** The Panel stated the necessity of cost-benefit and cost-effectiveness studies in order to justify funding, and discussed the importance of understanding costs and benefits in multiple contexts. Accordingly, the Panel recommends that studies of respite are specific to the contexts in which respite occurs, and that studies include measures relating to overall cost, costs that would reasonably be expected to occur in the absence of respite, costs borne by different parties associated with the respite model, and outcomes for both respite-receiving caregivers and caregivers not receiving respite.

4) **Research systems change that improves respite access.** 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.
5) **Research improving respite provider competence.** Existing research led some panel members to question whether the provision of respite by providers who lacked training specific to the needs of care receivers might lead caregivers to be reticent about using respite. While acknowledging that not all respite must be provided by people with special training, if special training is needed, the Panel recommends conducting research on the quality of available training curricula and on the most appropriate credentialing criteria for respite providers.

6) **Conduct translational research that informs respite policy and practice.** The Panel acknowledges that while statistically significant findings are the end goal for any research study, they also acknowledge that these findings do not necessarily translate automatically to findings or models that can be broadly or easily implemented. The Panel recommends consideration of the multiple factors in the implementation environment including: contextual variables; an organization’s readiness to change; implications for resources such as personnel requirements, training, record keeping, and accounting; and attention to details at the level of caregivers and the social and political contexts within which services are provided.

Detailed recommendations in each category can be found in the body of the report beginning on page 25. The research and deliberations upon which the Expert Panel based these recommendations also may be found in the [full report](#). It is the Panel’s hope that these recommendations will advance our collective understanding of how to best provide respite care that results in maximum benefits to care receivers and their families, and maximizes resources invested to accomplish these.

Excerpted from Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders, ARCH National Respite Network and Resource Center

This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.