

Alignment of CARR Work Groups to Key Recommendations

The following table shows the alignment of the CARR Work Groups to key recommendations from various national initiatives. Understanding the impact of the COVID-19 on respite is a cross-cutting issue that all CARR Work Groups will consider. Family caregivers must be recognized, engaged, and supported as key partners in this work. Additionally, strong advocacy for increased funding for respite research across the lifespan is critical.

CARR Work Group	<u>ARCH Expert Panel on Respite Research</u>	<u>ARCH Respite Summit</u>	<u>RAISE Family Caregivers Act Initial Report to Congress</u>	<u>SGRG Act Initial Report to Congress</u>
<p>Work Group 1 Define and measure the value (cost-effectiveness) of respite</p> <p>Members Ken Genewick Sarah Swanson Joe Caldwell Sue Peschin</p>	<p>Recommendation 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</p>	<p>Review Roundtable 2 Notes (p. 33-36)</p> <ul style="list-style-type: none"> • Collect longitudinal data • Coordinate data collection across systems • Collect data with the intention of informing policy • Measure in human terms • Foster greater federal collaboration to broaden meaningful data collection • Need to “re-think” cost-effectiveness and cost-benefit studies 	<p>Recommendation 2.4: Ensure the impact of policy and practices on family caregivers are studied and understood before changes are made in health care systems.</p> <p>Recommendation 4.1: Decrease the negative financial impacts for family caregivers on both a short- and long-term basis.</p> <p>Recommendation 4.4: Improve the affordability of long-term services and supports and reduce out-</p>	<p>Recommendation 4.1: Promote policies that prevent Kinship and Grandfamily caregivers from being financially disadvantaged by their caregiving responsibilities.</p> <p>Recommendation 5.2: Increase, support, and sustain research and development including adequate investments for evaluation of programs that support Kinship Families and Grandfamilies.</p>

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	<p>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.</p>	<ul style="list-style-type: none"> • Consider looking at health care utilization by caregiver and care receivers as a dyadic unit of analysis • Focus on costs to caregivers (out-of-pocket costs, loss of income, etc....) • Look at “value” versus “cost” 	<p>of-pocket costs for families through public and private payers.</p> <p>Recommendation 5.3: Increase the promotion, translation, and dissemination of promising and evidence-informed practices to support family caregivers in the delivery of health care and long-term services and supports.</p>	
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<p>Work Group 2 Recommend common data elements (CDE) for respite-related research</p> <p>Members Rebecca Utz Tamar Heller Tom Caprio Cordelia Robinson Rosenberg Sarah Sobotka</p>	<p>Recommendation 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</p>	<p>Review Roundtable 1 Notes (p. 30-32)</p> <ul style="list-style-type: none"> • Use a consistent definition of respite • Build upon existing data collection and tracking systems • Measure Quality of Life • Measure outcomes related to the human ecology 	<p>Recommendation 5.1: Establish a national infrastructure using standardized data, questions, and definitions for obtaining, analyzing, and disseminating information about caregivers and their experiences.</p>	<p>Recommendation 5.1: Establish a national approach for obtaining, analyzing, and disseminating relevant data on Kinship Families and Grandfamilies.</p>

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	address these shortcomings from the perspectives of research design, construction of independent and dependent variables relating to respite services, and methods and statistical analyses	<ul style="list-style-type: none"> • Coordinate data across programs, agencies and systems • Capture baseline data and take stock of what exists • Focus on positively worded or strength-based measures and avoid deficit-based measures • Consider Goal Attainment Scaling 		
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<p>Work Group 3 Expand culturally appropriate research with hard-to-reach or-serve populations</p> <p>Members Lauren Parker Rani Snyder Joseph Gaugler Kim Whitmore</p>	<p>Recommendation 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</p>	<p>Review Roundtable 3 Notes (p. 36-38)</p> <ul style="list-style-type: none"> • Collect data on underrepresented populations and services • Use “Ambassadors” to reach and better understand underserved populations 	<p>Recommendation 5.2: Increase family caregiver research that facilitates the development and delivery of programs and services that support and enhance the health and well-being of the caregiver and the person receiving support.</p> <p>Rationale: Research is needed to better document the needs and</p>	<p>Recommendation 3.2: Increase the availability of high quality, setting-appropriate and Kinship Family and Grandfamily-centered respite and childcare services.</p> <p>Recommendation 3.4: Increase the availability of supports and services that specifically meet the needs of the caregiver.</p>

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	<p>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.</p>	<ul style="list-style-type: none"> • Advocate for respite as a key service across diverse populations • Engage caregivers and care receivers in research process • Use accessible, respectful, and culturally appropriate language 	<p>impact of caregiving on diverse types of caregivers across the lifecourse.</p> <p>Recommendation 2.2: Engage family caregivers through the use of evidence-supported and culturally sensitive family caregiver assessments to determine the willingness, ability, and needs of family caregivers to provide support.</p> <p>Recommendation 3.1: Increase access to meaningful and culturally relevant information, services, and supports for family caregivers.</p>	
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