



A Program of Families and Communities Rising, Inc.

November 6, 2023

Agency for Healthcare Research and Quality (AHRQ)

Re: Comments on AHRQ Technical Brief Protocol for the *Evidence Map on Home and Community Based Services (HCBS) project*

On behalf of the ARCH National Respite Network and Resource Center, we, the undersigned members of the ARCH Committee for the Advancement of Respite Research, thank you for the opportunity to comment on AHRQ's **Technical Brief Protocol for the *Evidence Map on Home and Community Based Services (HCBS) project***.

The ARCH National Respite Network and Resource Center (ARCH) is funded by the Administration for Community Living to provide training and technical assistance to expand and improve respite options for the nation's family caregivers. Since 2020, ARCH has convened an expert [Committee on the Advancement of Respite Research](#) (CARR). Through this initiative, ARCH is striving to build a stronger evidence base for respite care that has shown promise in alleviating family caregiver stress and improving family caregiver well-being.

ARCH applauds AHRQ for engaging in this important review that will summarize service categories of HCBS, effectiveness of these interventions for specific conditions, and quality measures relevant to HCBS. The gaps in the evidence base that you identify will also help inform ARCH's ongoing [Respite Research Initiative](#). We offer the following recommendations for your consideration to help strengthen and align this important work.

Recommendation 1:

A CARR workgroup on advancing cost-benefits research on respite care recently developed a [White Paper on Measuring the Value of Respite](#) and proposed a [new framework](#) for conducting this research. In the [Value of Respite Model](#), the caregiver is interconnected with the care receiver. Guiding question 1d asks "What mediating factors have been identified in the literature that could affect outcomes such as the presence of unpaid family caregivers as part of the overall care team?" This is an important question. We compel AHRQ to recognize the important role of family caregivers and encourage the inclusion of outcome measures that are not only person-centered, but caregiver- and family-centered. In the face of the workforce crisis, family caregivers are more critical than ever to assurances of continuous care. Finding the optimum strategies to support them so that they can continue to provide care are central to the future of a successful long-term services and support system.

Recommendation 2:

In your list of interventions, we urge you to include **respite care services**. Respite care has been given added impetus with the recent release of the [National Strategy to Support Family Caregivers](#) from the Administration for Community Living. Expansion of flexible and meaningful respite care services is a theme that runs throughout the Strategy.



Recommendation 3:

In the Technical Brief Protocol, AHRQ acknowledges the challenge related to a “lack of consensus in outcome measures.” We agree this is a major challenge and are excited to share that the CARR will soon be releasing recommended common data elements for respite research to help improve the quality and comparability of research across respite models, populations served and respite dosage. We encourage AHRQ to consider using these common data elements as a framework for identifying potential outcome measures.

Recommendation 4:

We encourage AHRQ to broaden the focus of the review beyond adults aged 60 or older with a functional limitation and include other populations who receive HCBS interventions.

Recommendation 5:

Another area that is sorely in need of additional research is evaluation of culturally adapted and linguistically competent respite and family support interventions that result in positive family caregiver outcomes among diverse populations, especially with historically marginalized and underrepresented groups. Guiding question 1b. asks “What populations have been studied with person-centered HCBS interventions?” We encourage AHRQ to be intentional and explicit about the need to understand the cultural and linguistic appropriateness of HCBS interventions and the potential disparities in outcomes that may exist across populations.

Recommendation 6:

We value the inclusion of patient advocates as key informants in this work and urge AHRQ to consider expanding their engagement efforts to include additional key informants to ensure broad representation of the diversity of patients and caregiver perspectives, including, but not limited to the following groups: African American, Latinx, immigrant populations, members of the LGBTQ community, youth caregivers, grandparents raising grandchildren, and other forms of kinship care. If funding allows, we also recommend creating a more formal community advisory board (CAB) that could be engaged throughout the project to help review and inform the process and review and validate preliminary findings and recommendations.

Recommendation 7:

We recommend you include “preferred language” in the subgroup analysis in order to better understand the challenges related to linguistic barriers within HCBS interventions.

Recommendation 8:

We recommend doing a positive reframe of the KI question “What **burdens or harms** do patients have regarding the use of HCBS compared with alternatives (such as nursing homes, long-term care)?” and instead ask “What **benefits** do patients have regarding the use of HCBS compared with alternatives?” and “What are the **opportunities for improvements** of HCBS interventions?”

Please feel free to contact Jill Kagan, MPH, ARCH Director at 703.256.2084 or by email at jkagan@archrespite.org if you have any questions or require additional information.

Respectfully submitted,

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