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*A Program of Families and Communities Rising, Inc.*

October 13, 2023

## **National Institute on Disability, Independent Living, and Rehabilitation Research**

### **Re: NIDILRR's Draft 2024-2028 Long-Range Plan**

Thank you for the opportunity to comment on **NIDILRR's Draft 2024-2028 Long-Range Plan**. The ARCH National Respite Network and Resource Center 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. This work has been given added impetus with the recent release of the [National Strategy to Support Family Caregivers](#). Expansion of flexible and meaningful respite care services is a theme that runs throughout the Strategy.

Given that at least 60-75 percent of adults with developmental disabilities live at home with family, ARCH feels that NIDILRR should include specific mention of the need for research focused on family caregiver outcomes as a result of supportive, person and family-centered interventions, including respite. A significant number of these family caregivers are over age 60 (over 716,200 older caregivers) and face their own challenges, including age-related functional declines and concerns about what will happen to their relatives when they can no longer provide care.

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. 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. The CARR will also soon be releasing recommended common data elements in future respite research to improve the quality and comparability of research across respite models, populations served and respite dosage.

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 marginalized and underresourced groups.

Finally, the crisis in the shortage of qualified direct care workers is well established. What is not as well researched is the importance of the direct care workforce to supporting family caregivers through the provision of home care and respite services, and documenting the benefits to family caregiver and care recipient wellbeing of a well-trained and competent provider workforce.



ARCH partnered with the National Academy for State Health Policy to conduct a field test of a competency-based [respite provider training curriculum and unique recruitment strategies](#). A set of [respite provider core competencies](#) were developed by an expert work group convened by ARCH. Ten pilot states participated in the field test. Evaluation results are expected early in 2024 along with a replication toolkit. NIDILRR should consider further research to document the long-term effects of such training on building and sustaining the workforce, and on family caregiver and care recipient measures of well-being.

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.

We encourage NIDILRR to consider supporting respite research and research on family caregiver well-being more broadly in its long-range plan. The ARCH Committee for Advancement of Respite Research stands ready to assist you in these efforts.

Please feel free to contact me at 703.256.2084 or by email at [jkagan@archrespite.org](mailto:jkagan@archrespite.org) if you have any questions or require additional information.

Respectfully submitted,

  
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