

National Strategy to Support Family Caregivers

Public Comments Due November 30th

<https://acl.gov/CaregiverStrategy/Comments>

Which component of the strategy are you addressing with your comment?

- The 2022 National Strategy to Support Family Caregivers narrative
- Federal Actions
- Actions for States, Communities, and Others
- First Principles: Cross-cutting Considerations for Family Caregiver Support
- Global comment for all four components**

Please let us know how you are involved in caregiving. Which of the following best describes your role? (Select all that apply.)

- A family caregiver
- Employed by an organization that serves family caregivers
- Employed by a government program that serves family caregivers
- An advocate for family caregivers
- A researcher on caregiving topics
- Other/Prefer not to say**

Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward? (1500 characters limit)

The ARCH National Respite Network and Resource Center applauds the Advisory Council for their work on *Goal 5: Expand data, research, and evidence-based practices to support family caregivers* and encourages the inclusion of respite-related research as a focus moving forward.

A current initiative of ARCH is to collect, synthesize, disseminate, and stimulate research to improve respite practice and sustainability (<https://archrespite.org/respite-research>). The Expert Panel on Respite Research, convened by ARCH in collaboration with the Administration for Community Living, was key to helping advance this mission by engaging experts in the field in informed discussions of current respite research and possibilities for future investigation. A final report, including a respite research agenda, was released in October 2015. ARCH built a Respite Research Consortium to link interested researchers and funders to engage in respite research that follows the research framework developed by the Expert Panel, and to help implement the Expert Panel's research recommendations. A virtual Respite Research Summit

was held in September 2020, to evaluate the status of progress made to date and to identify next steps. ARCH recently formed the [Committee for Advancement of Respite Research \(CARR\)](#) that is charged with leading the next phase of this effort and identifying additional goals. Our recommendations for the National Strategy are based on the findings of these initiatives.

Are there issues that are not covered in this component that should be addressed in future updates? (1500 characters limit)

The Advisory Council should discuss and consider the following in future updates:

- Research recommendations should align with the ARCH Initiative to Advance a Research Agenda (archrespite.org/respite-research), including priority areas for research identified by the CARR: define and measure the value of respite (cost-benefits); recommend common data elements for respite-related research; and expand culturally appropriate respite research with hard-to-reach or-serve populations.
- The Council should recommend a funding announcement from the NIH, PCORI, or other funder to conduct caregiving research across the lifespan that aligns with the Recommendations for Future Respite Research described in the Expert Panel’s Research Agenda for Respite Care.
- The Council should recommend NIDILRR (or other funder) fund a National Respite Research Center.
- Existing national surveys (i.e., BRFSS, NHIS, NHANES, NSCH) should have additional and more robust questions that help identify family caregivers and family caregiver supports, including respite care.
- CMS should require caregiver assessments (including respite questions) in all programs that provide home and community-based services and issue guidance to States.
- CMMI should fund demonstration projects in Medicaid and Medicare to measure the outcomes of family caregiver supports, including respite care.
- Medicaid should consistently report claims data to show which States are funding respite and how much is billed.

If you have additional comments on any aspect of the Strategy, please provide them below. (500 characters limit)

The Strategy should continue to focus across the lifespan and more explicitly address the unique needs of caregivers of children and young adults with special needs, and adults between the ages of 18-60 with physical and intellectual/developmental disabilities, chronic conditions, and mental illness, and youth caregivers. While supporting current initiatives is important, additional resources are needed to initiate new programs and advance research to support family caregivers.