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## **Comments of ARCH and the National Respite Coalition on the *National Strategy to Support Family Caregivers***

### **Comments on FEDERAL ACTIONS**

#### **Within this component of the strategy, what are the three most important topics/issues for the Advisory Councils to focus on moving forward?**

ARCH has identified 3 priority areas for consideration: 1) ARCH applauds federal agencies' commitment to better support family caregivers. However, without new federal funding, meaningful change in how federal agencies currently support family caregivers will be hard to achieve. The Councils should develop an organized state-by-state advocacy strategy to secure additional federal resources, especially for home and community-based services, including respite, and to build and strengthen a stable direct care workforce. ACL should take the lead in future HHS budget justifications to Congress, in collaboration with other federal agencies, to include increased funding requests for programs in their jurisdiction that support family caregivers. 2) The Councils should enhance their focus on continuing to ensure a lifespan approach to family caregiving. A majority of family caregivers are caring for someone under age 75, including 14 million children and youth with special health care needs. Family caregivers of disabled and chronically ill adults ages 18-60 are the least likely to be eligible for publicly funded services. Federal strategies to support these groups, including young caregivers, should be included in all discussions. 3) The Councils should explore ways that the federal government can better serve those family caregivers who earn too much to be eligible for Medicaid, but too little to pay for critically needed services.

#### **Are there issues that are not covered in this component that should be addressed in future updates?**

ARCH recommends the Councils consider the following federal actions:

- 1) Assist all states in adopting the federal Lifespan Respite Care Program as a model to build statewide coordinated systems of caregiving and respite services for family caregivers caring for persons of any age or condition. Lifespan Respite grantees have demonstrated how to provide family and person-centered services; assist families in paying for care through self-directed voucher programs; developed innovative volunteer and faith-based models; built diverse coalitions; recruited and trained respite workers; and improved access to information and support through no wrong door systems.
- 2) Make permanent eligibility, setting and provider flexibilities approved for Medicaid waiver HCBS under COVID-19.

- 3) Ensure respite is included or expanded as a benefit in Medicaid Managed Long term Services and Supports contracts and Medicare Advantage plans.
- 4) Add respite as a benefit in traditional fee-for-service Medicare
- 5) Expand respite care benefits in Medicare/Medicaid hospice to allow alternative settings, including home-based services.
- 6) Add the following federal agency representatives to the Councils: Maternal and Child Health Bureau, HRSA, Early Intervention and Office of Special Education, Department of Education to ensure inclusion of caregivers of children; Dept of Labor to address working caregiver issues; and USDA cooperative extension to address needs of rural caregivers.

**If you have additional comments on any aspect of the Strategy, please provide them below.**

The ARCH National Respite Network and Resource Center applauds the National Strategy's approach to addressing the importance of diversity, equity and inclusion in all aspects of the report. We urge that future Councils continue to elevate the importance of cultural and linguistic competency in all modes of family caregiver service delivery and support, and that they recommend increased funding for additional and ongoing research to expand our knowledge base in this area.

*Prepared by ARCH in November 2022 in response to a call from the Administration for Community Living for feedback on the National Strategy to Support Family Caregivers. Responses will be used to help the RAISE Family Caregiving Advisory Council and the Advisory Council on Supporting Grandfamilies Raising Grandchildren identify priorities for future updates of the Strategy.*