



Toolkit: Lifespan Respite “101”

Opportunities for Collaboration in the Federal Application Process for Lifespan Respite Funding

Background: For States to receive a federal grant to implement a Lifespan Respite Program, eligible state agencies¹ must compete for funds by responding to a Funding Opportunity Announcement (FOA) on the availability of federal funds issued by the U.S. Department of Health and Human Services, Administration for Community Living. While additional information could be required in future FOAs, each one since 2009 has required that the information outlined below be included in the state agency’s application.²

Action: Compiling information for the application will require research, documentation, and planning. These activities present opportunities for collaboration among required partners early in the planning process, before funds are awarded. Required partners include a State Respite Coalition, an Aging and Disability Resource Center/No Wrong Door System (ADRC/NWD), and the lead state government agency. Each partner should consider how they could be most helpful with any or all of the requirements below, and state agencies should consider with which requirements they may need assistance and develop a timeline to complete the tasks.

Application must include descriptions of:

- the state’s population of family caregivers;
- the extent and nature of the respite care needs of that population;
- existing respite care services for that population, including numbers of family caregivers being served and extent of unmet need;
- existing methods or systems to coordinate respite care information and services to the population at the State and local level and extent of unmet need;
- how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using funds provided under this announcement;
- a plan for administration, collaboration, and coordination of the proposed respite activities with other related services or programs offered by public or private, nonprofit entities, including Area Agencies on Aging; Centers for Independent Living, community-based organizations providing support to people with disabilities, faith-based entities and ADRCs/NWD.
- how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of the proposed respite care activities;
- how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contributions, and other resources, such as reimbursements, personnel, and facilities;
- the criteria used to identify family caregivers eligible for respite care services;

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¹ State agencies eligible to apply for a Lifespan Respite Grant are agencies which administer the Older Americans Act, the state Medicaid Agency, or an agency designated by the Governor.

² Previous Lifespan Respite FOAs from ACL are archived at <https://archrespite.org/ta-center-for-respite#ArchivedPAs>

- respite care services available to family caregivers in the eligible State agency's State or locality, including unmet needs and how the eligible State agency's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of children and adults with special needs;
- how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver;
- measures to be taken to ensure confidentiality of individuals served by the program;
- a plan for the project's sustainability; and
- the results expected from proposed respite care activities and the procedures to be used for evaluating those results.³

Application must also include:

- a memorandum of agreement regarding the joint responsibility for the eligible State agency's lifespan respite program between the eligible State agency, and a public or private nonprofit statewide respite coalition or organization.⁴

Possible Roles/Activities for Partners in Collaboration:

- 1) Conduct statewide needs assessment using sources, such as Census data and demographic information to compile the numbers of individuals with disabilities or chronic conditions.
- 2) Conduct an environmental scan of available respite services by surveying respite programs, home health agencies, adult daycare, community and faith-based organizations, volunteer groups (e.g., Girl Scouts), child care programs, state-level private disability, children's and aging organizations to document respite services available at the state and local levels.
- 3) Survey respite programs and family caregivers about respite availability to determine which age and disability groups are served, underserved, or unserved.
- 4) Update respite directories previously compiled by the ADRC, state respite coalition or other organization.
- 5) Work with university or research-based organization to conduct statewide randomized telephone survey or use other survey methods to determine the numbers of family caregivers statewide, for whom they provide care, and whether or not they use respite.
- 6) Survey state agencies to identify and catalogue all federal and state respite funding sources used by the state, those that potentially could be used to support respite, and eligibility requirements and/or waiting lists tied to these funding sources.
- 7) Hold focus groups or roundtables with family caregivers and providers statewide to gather personal stories about the need for respite services and preferred options for respite care.
- 8) Form a planning group with representatives from state agencies, the state respite coalition, respite providers, family caregivers, ADRCs and other stakeholders to design your state's Lifespan Respite system, select measurable outcomes, and develop a sustainability plan.

³ FY 2016 Lifespan Respite Care Program: Grants to New States. Funding Opportunity Number: [HHS-2016-ACL-CIP-LRLR-0166](#)

⁴ Ibid.

