



Fact Sheet: Opportunities for Collaboration in the Federal Application Process for Lifespan Respite Funding

Background: Before a state is awarded a federal grant to implement a Lifespan Respite Program, it must complete an application to be submitted to the US Department of Health and Human Services and compete with other states for funds. The Lifespan Respite law requires that the information outlined below be included in the application. The federal program announcement for FY 2009 followed the law very closely. Compiling this information for the application will require research, documentation, and planning, which presents opportunities for state respite coalition, Aging and Disability Resource Center, and state agency collaboration early in the implementation process. 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 might need assistance.

Federal Application Requirements

Application must include descriptions of:

- The population of family caregivers -- who are the family caregivers and how many are there in the state;
- 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 grant or cooperative agreement funds; Which Lifespan Respite system model will work best in your state?
- a plan for administration, collaboration, and coordination of the proposed respite care activities with other related services or programs offered by public or private, nonprofit entities, including area agencies on aging;
- 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, other forms of reimbursements, personnel, and facilities;

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- 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;
- the criteria used to identify family caregivers eligible for respite care services;
- 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; and
- the results expected from proposed respite care activities and the procedures to be used for evaluating those results.

Application must also include:

- assurances that, where appropriate, the eligible State agency will have a system for maintaining the confidentiality of care recipient and family caregiver records; and
- 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.

Possible Roles for State Respite Coalition/State Respite Organization/ADRCs/ State Agency Collaboration:

- 1) Conduct statewide respite needs assessment of demographic information
- 2) Survey respite programs, home health agencies, adult daycare, community-based organizations, faith-based groups, volunteer groups (e.g., Girl Scouts), schools and child care programs, state-level private disability, children's and aging organizations to document the respite services that are already available at the local level, and determine which age groups and disabling or chronic conditions are served, or update respite directories already compiled by state respite coalition or organization.
- 3) Work with university or other research based organization to conduct statewide randomized telephone survey to determine the numbers of family caregivers statewide, who they provide care for, and whether or not they use respite.
- 4) Survey state agencies to identify and catalogue all federal respite funding sources already used by the state, those that could potentially be used to pay for respite, and any state revenue used to support respite, and eligibility requirements and/or waiting lists tied to these funding sources.
- 5) Hold focus groups or roundtables with family caregivers and providers around the state to gather personal stories about the need for respite services and the preferred form of respite service delivery.

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