



**United States Government Accountability Office
Washington, DC 20548**

October 22, 2010

The Honorable Tom Harkin
Chairman
The Honorable Michael B. Enzi
Ranking Member
Committee on Health, Education, Labor and Pensions
United States Senate

The Honorable Henry A. Waxman
Chairman
The Honorable Joe Barton
Ranking Member
Committee on Energy and Commerce
House of Representatives

Subject: *Respite Care: Grants and Cooperative Agreements Awarded to Implement the Lifespan Respite Care Act*

Individuals who are limited in their capacity for self-care because of a physical, cognitive, or mental disability or condition that results in a functional impairment may depend on family caregivers for assistance with routine daily activities. According to a 2009 study by the National Alliance for Caregiving and AARP, an estimated 65.7 million people, or 29 percent of the population, had served as unpaid family caregivers to an adult or child with special needs in the previous 12 months, providing an average of about 20 hours of care per week.¹ Activities caregivers conduct can range from assistance with routine daily tasks like bathing and dressing, to carrying out more complex health-related interventions like administering medication and wound care. The responsibilities of caregiving may present physical, emotional, and financial challenges for caregivers.

Caregivers can receive temporary relief from their caregiving responsibilities through the use of *respite care*—planned or emergency care provided to an adult or child with special needs, such as an individual with muscular dystrophy, traumatic brain injury, or dementia. Respite care may be provided in a variety of settings, including homes, adult day care centers, or residential care facilities. Research has shown respite care to have benefits for both the caregiver and care recipient, such as reducing stress and improving the physical and emotional health of the caregiver, while reducing the likelihood of hospitalization or

¹National Alliance for Caregiving/AARP, *Caregiving in the U.S. 2009* (November 2009). A child with special needs requires care or supervision beyond that required of children generally to meet his or her basic needs or prevent injury, such as a child with a medical, behavioral, or other condition or disability.

institutionalization of the care recipient.² However, according to the 2009 family caregivers study by the National Alliance for Caregiving and AARP, only 12 percent of caregivers have used respite care services.³

Funding for respite care can come from a variety of sources, including the federal government, state governments, or other sources such as private foundations. Federal funding for respite care may be available under various programs.⁴ For example, the Medicaid Home and Community-Based Waiver Program permits states to pay for respite care services, and the National Family Caregiver Support Program, authorized by the Older Americans Act of 1965, as amended, provides funds to each state to provide information to caregivers about available services, including respite care.⁵ Programs that provide funding for respite care, however, often have specific eligibility criteria, based, for example, on age, disability, or family income. The disparate nature of funding streams and eligibility requirements for respite care may result in challenges for families, such as waiting lists, complex application processes, or difficulty finding providers able to deliver respite care appropriate to their particular needs and situation.

In December 2006, the Lifespan Respite Care Act of 2006 (LRCA) was enacted to improve the delivery and quality of respite care services available to families across age and disability groups by establishing coordinated lifespan respite systems.⁶ The LRCA authorized the Secretary of the Department of Health and Human Services (HHS) to award competitive grants or cooperative agreements to eligible state agencies⁷ to: (1) expand and enhance respite care services to family caregivers; (2) improve the statewide dissemination and coordination of respite care; and (3) provide, supplement, or improve access and quality of respite care services to family caregivers. The LRCA also authorized the Secretary of HHS to

²For example, see: Susan L. Folden and Sherrilyn Coffman, "Respite Care for Families of Children with Disabilities," *Journal of Pediatric Health Care*, vol. 7, no. 3, (1993); and Saundra L. Theis, Joan H. Moss, and Merry Ann Pearson, "Respite for Caregivers: An Evaluation Study," *Journal of Community Health Nursing*, vol. 11, no. 1 (1994).

³National Alliance for Caregiving/AARP, *Caregiving in the U.S. 2009* (November 2009).

⁴In the future, the Patient Protection and Affordable Care Act may provide another potential source of funding for respite care, as it established a national, voluntary insurance program for purchasing community living services and supports, including respite care, known as the Community Living Assistance Services and Supports (CLASS) program. Pub. L. No. 111-148, §§ 8002, 10801, 124 Stat. 119, 828-47, 1015. The CLASS program was designed to provide individuals with functional limitations with tools that will allow them to maintain their personal and financial independence. Examples of the services and supports that can be purchased include respite care, as well as nursing support, assistive technology, home modifications, personal assistance services, accessible transportation, and homemaker services. The CLASS program becomes effective on January 1, 2011. The Secretary must designate a benefit plan by October 1, 2012. Certain adults who contribute to the program for at least 5 years may qualify to receive a minimum average benefit of \$50 a day, if they have a qualifying level of disability or cognitive impairment.

⁵Medicaid is a joint federal-state program that finances health care for certain categories of low-income adults and children. Social Security Act § 1915(c)(4)(B), codified, as amended at 42 U.S.C. § 1396n(c)(4)(B). Older Americans Act §§ 371-74, codified, as amended, at 42 U.S.C. §§ 3030s through 3030s-2.

⁶Pub. L. No. 109-442, 120 Stat. 3291.

⁷Eligible state agencies are those that administer a state's program under the Older Americans Act of 1965; a state's program under title XIX of the Social Security Act (Medicaid); or are designated by a Governor to administer a state's LRCA program. Additionally, an eligible state agency must work in collaboration with a public or private non-profit statewide respite care coalition or organization, and must be an Aging and Disability Resource Center, which provides information and assistance to older adults and people with disabilities about long-term care services and support. For the purposes of the LRCA, the term 'state' refers to any of the 50 states, the District of Columbia, the U.S. Virgin Islands, Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands.

award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care to: (1) maintain a national database on lifespan respite care; (2) provide training and technical assistance to state, community, and nonprofit respite care programs; and (3) provide information, referral, and educational programs to the public on lifespan respite care. For fiscal years 2007 through 2011, over \$289 million was authorized to carry out activities under the Act.

Since the enactment of the LRCA, \$5 million has been allocated to date to implement the federal Lifespan Respite Care Program—\$2.5 million in each of fiscal years 2009 and 2010. The Administration on Aging (AOA), the agency within HHS responsible for administering the Lifespan Respite Care Program, has had two competitive grant announcements for state agencies, with funding starting in September 2009 and September 2010 respectively. Both announcements offered federal funding of up to \$200,000 per award for a 3-year project period; grantees are required to provide at least a 25 percent match of total project costs. In addition, in May 2009, AOA announced the availability of funding for a public or nonprofit entity to enter into a cooperative agreement with AOA to provide caregiver and respite program development and technical assistance, including establishing the National Resource Center on Lifespan Respite Care.⁸

The LRCA required that GAO evaluate lifespan respite programs. This report describes the grants and cooperative agreements that have been awarded to implement the requirements of the LRCA.⁹

To address this objective, we interviewed officials from AOA and reviewed related documentation including grant applications, notice of awards, grantee work plans, and semi-annual progress reports. We also interviewed the program director of the ARCH National Respite Network and Resource Center (ARCH) to obtain background information on respite care and information about the National Resource Center on Lifespan Respite Care. ARCH is a nonprofit organization that works to assist and promote the development of quality respite care programs by providing training and technical assistance to state and local respite care programs, and helping families locate respite care services in their communities.

We conducted this performance audit from July 2010 through October 2010 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

⁸This announcement provided for up to \$350,000 in federal funding per year for 3 years, pending availability of funding. For each year that funding is available to support this cooperative agreement, half of the funding will be drawn from the LRCA funds, while the other half will come from Older Americans Act funds.

⁹As discussed with the cognizant committees, due to the timing of the grant funds awarded to date—with the first grants awarded in September 2009—it was not possible to evaluate the effectiveness of the funded programs by the mandated deadline.

AOA Has Awarded 24 Grants and One Cooperative Agreement to Implement LRCA Requirements

AOA awarded a total of almost \$5 million through 24 LRCA grants and one cooperative agreement in 2009 and 2010.¹⁰ Specifically, AOA awarded grants to agencies in 24 states—12 states in September 2009 and 12 states in September 2010.¹¹ The grants, which provide funding for a 3-year project period, ranged from \$110,000 to \$200,000. Grants totaled \$2,293,378 and \$2,254,078 in 2009 and 2010, respectively. States plan to use the grant funds for a variety of activities including respite care provider training, the development of respite care provider registries, public awareness and education initiatives, and improving coordination across the various agencies that handle respite care services. (See encl. I for more information about the award amount, project objectives, and planned activities of each state grantee.)

In addition to the state grants, AOA awarded a 3-year cooperative agreement to the Family Caregiver Alliance (FCA) in September 2009 to provide caregiver and respite care program development and technical assistance; FCA subcontracted with ARCH for the respite care portions of the cooperative agreement.¹² As of September 2010, ARCH had received a total of \$381,622 in LRCA funds through its contract with FCA—\$206,622 in September 2009 and \$175,000 in September 2010.¹³ ARCH is using these funds for activities such as providing in-person and web-based training, conducting site visits of state grantees, preparing and updating fact sheets and issue briefs on respite care, preparing quarterly technical assistance newsletters, and updating an online respite care locator service.

Agency Comments

We provided a draft of this report to HHS for review and comment. In its comments, HHS indicated that the report provided an excellent overview of the department's efforts, to date, to implement the Lifespan Respite Care Program and was a useful resource for anyone interested in learning about the development of respite care systems (see encl. II). HHS also provided technical comments that we incorporated as appropriate.

We are sending copies of this report to the Secretary of Health and Human Services. In addition, the report will also be available at no charge on the GAO website at <http://www.gao.gov>.

¹⁰Of the \$5 million allocated to date to implement the LRCA, AOA has awarded \$4,929,078 in grants and cooperative agreements, and reserved \$70,922 for evaluation and other administrative purposes.

¹¹In 2009, 18 states applied for grants, and 15 states applied in 2010. States that received funding under the 2009 program announcement were not eligible to apply for the 2010 grants.

¹²The respite care portion of the cooperative agreement was funded through LRCA funds while the caregiver portion was funded through the Older Americans Act.

¹³In addition to the \$381,622 in LRCA funds which were provided via subcontract to ARCH, FCA received \$350,000 in Older Americans Act funding (\$175,000 in each of 2009 and 2010) for its portion of the cooperative agreement. AOA awarded \$350,000 in both 2009 and 2010 under this cooperative agreement, and also provided an additional \$31,622 in supplemental LRCA funds in 2009.

If you or your staffs have any questions regarding this report, please contact me at (202) 512-7114 or draperd@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in enclosure III.



Debra A. Draper
Director, Health Care

Enclosures – 3

**Lifespan Respite Care Program State Grantees' Award Amounts, Project Objectives,
and Planned Activities**

Table 1: Award Amount, Project Objectives, and Planned Activities, by Fiscal Year 2009 Lifespan Respite Care Program Grantee

Grantee	Award amount	Project objectives	Examples of planned activities
Alabama Department of Senior Services	\$200,000	<ul style="list-style-type: none"> • Conduct a statewide public education campaign. • Explore new grant possibilities and other resource-generating opportunities. • Enhance the capacity of the Alabama Lifespan Respite Resource Network. • Identify all agencies and resources currently providing respite funding. • Identify all caregiver training programs. • Expand training for the staff of the Alabama Disability Resource Center and expand their website to include respite resources. • Work collaboratively with a range of partners to recruit and train respite care workers and volunteers. 	<ul style="list-style-type: none"> • Help communities establish "Sharing the Care" groups that utilize volunteer stakeholders.^a • Develop a training module and other materials for groups interested in implementing a "Sharing the Care" project. • Conduct a statewide survey to identify caregiver needs and provide information about gaps and barriers to respite care.
Arizona Department of Economic Security	199,128	<ul style="list-style-type: none"> • Expand the reach of the respite care program to include all caregivers that could benefit. • Ensure the program's effectiveness by making respite care more accessible, practical, and culturally sensitive. • Improve public awareness through a social marketing campaign and by establishing a toll-free respite care hotline. • Assure consistent delivery of respite care through implementation of a new caregiver assessment tool. • Coordinate provision of emergency respite to caregivers identified by Adult Protective Services. 	<ul style="list-style-type: none"> • Roll out a statewide public awareness campaign using radio, television, and print media, and a toll-free respite care hotline. • Complete a pilot program using a caregiver assessment tool as part of the authorization process for respite care.

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Grantee	Award amount	Project objectives	Examples of planned activities
Connecticut Department of Social Services	199,934	<ul style="list-style-type: none"> • Establish a database to identify all respite care services and funding sources in the state. • Promote networking by establishing working relationships between key agencies and organizations involved with respite care. • Provide public awareness and information. • Provide training opportunities to caregivers and service organizations. • Enable family caregivers to make informed decisions about respite care services. • Establish a single point of entry for all respite care services. 	<ul style="list-style-type: none"> • Establish training protocols according to age, disability, and other specialized needs. • Document available respite care services, provider options, and funding information in a database. • Hold focus groups for caregivers to assist them in determining suitable respite care options.
District of Columbia Office on Aging	199,999	<ul style="list-style-type: none"> • Expand and enhance respite care services by establishing the infrastructure for a lifespan respite program through recruitment and training. • Improve coordination and dissemination of service delivery between different programs. • Promote awareness of respite care programs. • Conduct a needs assessment and advocate for services that are not currently available. 	<ul style="list-style-type: none"> • Educate faith-based organizations about how to develop a group of trained volunteer respite care providers. • Conduct an evaluation to determine available resources, needs, and key stakeholders required to sustain the respite care program infrastructure and provide comprehensive services.
Illinois Department on Aging	200,000	<ul style="list-style-type: none"> • Create a respite care website. • Provide respite care services. • Improve collaboration among state agencies. • Train caregivers and volunteers. • Create a statewide respite taskforce. • Create a statewide toll-free respite number. • Provide technical assistance and training materials. • Create a public awareness campaign. • Evaluate the effectiveness of the project. 	<ul style="list-style-type: none"> • Create a respite care website that includes a list of providers by the geographical location and special need populations served, and a list of caregiver training opportunities. • Publicize the toll-free respite number via a media campaign and outreach to relevant individuals and organizations, such as medical providers, law enforcement agencies, and pharmacies.

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Grantee	Award amount	Project objectives	Examples of planned activities
Nevada Aging and Disability Services Division	200,000	<ul style="list-style-type: none"> • Create a “Respite Care Network” in partnership with several other organizations. • Improve the quality of respite care services by developing quality standards. • Provide group and individual training via web resources, interactive videoconference technology, face-to-face sessions, and DVDs. • Empower family caregivers to solicit, train and employ respite care volunteers. 	<ul style="list-style-type: none"> • Develop a “blog” for information sharing among partners, caregivers and respite care providers. • Establish a partnership with Nevada 2-1-1, a statewide information and referral call center, to train operators to recognize crisis situations and signs of caregiver burnout.
New Hampshire Department of Health and Human Services, Special Medical Services	110,000	<ul style="list-style-type: none"> • Select appropriate training modules for respite care providers. • Develop training modules on caring for those with Severe Emotional Disturbance (SED) or Traumatic Brain Injury (TBI). • Develop a marketing campaign to recruit providers and train those providers. • Create a registry of trained respite care providers. • Institute a pilot respite care program for those with SED. • Create an advisory group to oversee the program. 	<ul style="list-style-type: none"> • Create a registry of trained providers using web-based trainings including ones targeted for the SED and TBI populations. • Conduct outreach to potential respite care providers from multi-cultural backgrounds.
North Carolina Department of Health and Human Services	184,328	<ul style="list-style-type: none"> • Research, adapt, and implement a model Lifespan Respite Care Program. • Improve statewide coordination of respite care services. • Enhance infrastructure through new relationships with faith-based and medical communities. • Develop an innovative statewide respite care education and public awareness initiative. 	<ul style="list-style-type: none"> • Form a “State Stakeholder Advisory Team” to enhance access, identify gaps, and improve education and training. • Train North Carolina Baptist Aging Ministry volunteers to share respite information, plan and implement recruitment activities, and provide respite care services. • Increase the inventory of respite care resources in the state’s web-based health services information portal.
Rhode Island Department of Elderly Affairs	200,000	<ul style="list-style-type: none"> • Coordinate respite care through the state’s Medicaid program.^b • Expand the statewide TimeBanks program, a volunteer voucher program.^c • Disseminate information on respite care to clinics, physician offices, and support agency offices. 	<ul style="list-style-type: none"> • Help develop guidelines for the new Medicaid respite care benefit. • Publicize the TimeBanks program to increase volunteers and awareness. • Hire a coordinator to connect volunteers and those who need services.

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Grantee	Award amount	Project objectives	Examples of planned activities
South Carolina Lieutenant Governor's Office on Aging	199,989	<ul style="list-style-type: none"> • Establish a coordinated respite system that expands and enhances respite care services statewide. • Establish a State Advisory Council. • Provide outreach, information and screening for respite care services. • Disseminate information and training materials to family caregivers to mobilize social supports and encourage earlier and increased use of respite care. • Build capacity to recruit and train volunteer respite care providers, particularly in rural areas. 	<ul style="list-style-type: none"> • Update a web-based information system by identifying regional and local respite resources. • Conduct workshops at a minimum of four family or provider-oriented conferences each year. • Create a "ToolKit for Developing a Voucher Program within a Faith Community."
Tennessee Commission on Aging and Disability	200,000	<ul style="list-style-type: none"> • Facilitate coordination among respite care programs and providers. • Increase access through a "no wrong door" system that connects people to services regardless of which agency they first contact. • Develop a plan to collect and analyze data about the respite care needs of families and the provision of services. • Enhance the abilities of the Tennessee Respite Coalition to respond to needs through a Respite Specialist. • Increase opportunities for provider and caregiver training. • Increase respite care volunteer training. 	<ul style="list-style-type: none"> • Identify and collaborate with one college or university per year to establish volunteer respite training collaborations. • Provide case management services through the toll-free Helpline. • Develop a plan to implement a uniform statewide data collection system.
Texas Department of Aging and Disability Services	200,000	<ul style="list-style-type: none"> • Create the Texas Respite Coordination Center. • Increase the availability of respite care services. • Implement a caregiver awareness campaign. • Develop best practices, materials and tools for respite care providers. 	<ul style="list-style-type: none"> • Conduct five forums throughout the state to highlight training curriculums and best practices for recruiting providers and other capacity building resources. • Add a caregiver self assessment tool and links to statewide respite care resources to the state agency's website. • Compile and annually update an inventory of respite care services.
Total		\$2,293,378	

Source: GAO summary of information from the Administration on Aging's notice of awards and grantees' applications.

^aThe "Sharing the Care" model adopted by Alabama consists of local groups that utilize volunteer stakeholders living and working in a specific area to carry out activities related to public awareness and development of new respite care resources.

^bMedicaid is a joint federal-state program that finances health care for certain categories of low-income individuals. Rhode Island's Medicaid program, which has a goal to increase community living for individuals who may otherwise be placed in an institution, provides coverage for respite care services.

^cThe Time Banks program adopted by Rhode Island manages and tracks community currency called Time Dollars. Individuals earn Time Dollars for time they spend helping another person and can use the Time Dollars they earn to obtain services for themselves or others.

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Table 2: Award Amount, Project Objectives, and Planned Activities, by Fiscal Year 2010 Lifespan Respite Care Program Grantee

Grantee	Award amount	Project objectives	Examples of planned activities
Delaware Department of Health and Social Services	\$188,432	<ul style="list-style-type: none"> • Improve lifespan respite infrastructure. • Improve the provision of information and awareness about respite services. • Streamline access to respite services through the Delaware Aging and Disability Resource Center (ADRC).^a • Increase availability of respite services. 	<ul style="list-style-type: none"> • Expand an existing voucher program to serve more caregivers. • Open two new Caregiver Resource Centers outside of Senior Centers to appeal to a broader range of caregivers. • Enhance the respite care website to include individual respite workers in addition to agency-based providers.
Kansas Department on Aging	188,821	<ul style="list-style-type: none"> • Expand coordination, participation and dissemination of respite resources resulting in a statewide respite network. • Increase family caregiver access to respite care providers. • Increase availability of qualified respite care providers and skilled caregivers statewide. 	<ul style="list-style-type: none"> • Conduct statewide “listening tours” to convene individuals to discuss current respite care services and needs. • Provide free training opportunities and 20 respite care scholarships to caregivers who attend the listening tours.
Louisiana Department of Health and Hospitals, Office of Aging and Adult Services	188,838	<ul style="list-style-type: none"> • Enhance and coordinate information available about respite services. • Increase consumer knowledge and acceptance of respite services. • Increase the availability of respite care. 	<ul style="list-style-type: none"> • Encourage respite care providers to add their information to the ADRC database and use respite as a key word for their listing. • Implement a public awareness campaign including designating a “Caregiver Burnout Month” intended to provide an annual opportunity to promote respite care in the state.
Massachusetts Department of Developmental Services	188,950	<ul style="list-style-type: none"> • Develop and formalize the Massachusetts Respite Coalition. • Improve statewide dissemination and coordination of respite care by developing a comprehensive accessible directory of services. • Enhance and expand the availability of respite services by improving training and recruitment of providers and developing a strategic plan and list of policy recommendations. 	<ul style="list-style-type: none"> • Develop a survey of providers to assess existing respite care resources, eligibility criteria, and potential funding streams. • Create print and web-based directories of respite care resources. • Develop a set of minimum quality standards and written guidelines for respite care providers.

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Grantee	Award amount	Project objectives	Examples of planned activities
Minnesota Department of Human Services, Board on Aging	188,950	<ul style="list-style-type: none"> • Jumpstart, train and support Regional Lifespan Respite Collaboratives. • Enhance the listing of respite resources in the state's online database. • Expand the state's online page for caregivers to include more information on respite care resources. • Train community members as "lifespan respite ambassadors" to increase awareness. • Increase coordination among public programs. • Increase consumer choice and control of services. 	<ul style="list-style-type: none"> • Map existing respite resources seeking evidence of underutilization of resources, signs of latent capacity and opportunities to share resources. • Expand the state's online database to provide information and resources regarding respite care services. • Coordinate and enhance the quality assurance and monitoring process for all respite care workers.
Nebraska Department of Health and Human Services	178,322	<ul style="list-style-type: none"> • Replace existing respite care database with a web-based system. • Expand on-line assessments to include identification of respite needs and make respite referrals through the ADRC. • Expand peer support options available through the ADRC website. • Educate Lifespan Respite Program coordinators about the utility of the ADRC. • Educate family caregivers about the resources available through the ADRC. • Develop or identify a statewide caregiver crisis planning tool. • Identify respite care providers willing to provide crisis/emergency care. • Identify and develop training for first responders in need of information about emergency respite care. • Deliver training for first responders. • Develop criteria for providing very short-term crisis respite care funding. • Expand awareness of respite care services. 	<ul style="list-style-type: none"> • Bring respite provider information to the Nebraska Resource Referral System, a statewide human services database. • Create training materials for Lifespan Respite Program Coordinators and family caregivers.

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Grantee	Award amount	Project objectives	Examples of planned activities
New York State Office for the Aging	188,950	<ul style="list-style-type: none"> • Develop a coordinated system of accessible, community-based respite care services. • Conduct a statewide inventory of respite care services. • Identify and facilitate the development of respite care services for underserved populations. • Identify current programs that train caregivers and provide a methodology to link caregivers to programs. • Determine good recruitment and training practices and establish linkages to recruitment and training of volunteers. • Raise awareness about respite care. • Develop a strategic approach to ensure sustainability of respite care delivery and management. 	<ul style="list-style-type: none"> • Form a statewide caregiver network. • Conduct an inventory of all respite care services in order to build a comprehensive respite care database, which will be merged into the existing state resource directory. • Analyze the use of public funds and search for private funding opportunities.
Oklahoma Department of Human Services	188,950	<ul style="list-style-type: none"> • Provide technical assistance and seed grants to community groups to start or enhance respite care services. • Provide respite care vouchers to caregivers not eligible for funding. • Enhance statewide outreach and recruitment efforts through public speaking engagements and development of promotional materials. • Strengthen training collaboration. 	<ul style="list-style-type: none"> • Implement the Mobile Respite Pilot Project, which will provide respite care in non-traditional locations using a bus and a mobile respite team. • Provide caregiver training and education sessions. • Redesign and expand an existing respite guide to include information on new target populations and resources.
Pennsylvania Department of Aging	187,015	<ul style="list-style-type: none"> • Establish a statewide Lifespan Respite Care Advisory Council. • Improve coordination among state and local agencies and organizations that provide or fund respite care services and those that provide information and referrals to families. • Increase awareness of lifespan respite care needs and services. 	<ul style="list-style-type: none"> • Develop and administer a mini grant program targeted toward the provision of emergency and unplanned respite for caregivers. • Create a website with training opportunities and links to provider resources.
Utah Department of Human Services	188,950	<ul style="list-style-type: none"> • Institute a comprehensive respite care program with an accessible point of entry, a telephone helpline, and web-based access. • Expand respite care services and scholarships and develop private funding sources to sustain the scholarships. • Implement a new caregiver training program statewide and add modules to support non-service connected caregivers of veterans with dementia. • Facilitate training and job access for candidates entering the field of professional caregiving and provide volunteer training. 	<ul style="list-style-type: none"> • Organize a series of town hall meetings to inform participants about the state's respite care program. • Execute a Lifespan Respite Care Conference with 300 caregivers, agency and provider organization representatives. • Train 50 new respite care providers.

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Grantee	Award amount	Project objectives	Examples of planned activities
Washington Department of Social and Health Services	188,950	<ul style="list-style-type: none"> • Build the capacity of the respite coalition through new and existing partnerships. • Provide information to caregivers to enable them to recruit, hire, and work with respite care providers. • Collaborate on a statewide volunteer respite care model for the recruitment, training, support and retention of volunteer respite care providers. • Develop outreach strategies to inform the public about the single point of entry for inquiries about respite care. 	<ul style="list-style-type: none"> • Implement a partnership with Girl Scouts of Western Washington aimed at providing respite care services to caregivers of children living with relatives. • Increase Camp Fire USA outreach in advertising its summer day and residential camp programs to give caregivers respite.^b • Secure additional feedback from ethnic caregivers about their needs, perceptions, and barriers to respite care.
Wisconsin Department of Health Services	188,950	<ul style="list-style-type: none"> • Modify Easter Seals Wisconsin's training curriculum in order to use it as base-level training for all respite care providers. • Deliver the revised training curriculum in 6 different regions of the state. • Deliver half-day workshops in 6 different regions for respite care providers to learn best practices. • Develop a public awareness campaign. • Implement a statewide public awareness campaign. • Expand Wisconsin Quality Home Care Commission's care registry referral database to include trained respite workers. • Communicate respite care provider trainings and the expanded care registry to long-term care stakeholders. 	<ul style="list-style-type: none"> • Organize a series of training sessions for respite care providers to learn best practices for special populations. • Enter respite care providers into a web-based registry and matching service.
Total		\$2,254,078	

Source: GAO summary of information from the Administration on Aging's notice of awards and grantees' applications.

^aAn ADRC is a single point of entry into the long-term supports and services system that provides information and assistance to older adults and people with disabilities about long-term care services and support.

^bCamp Fire USA is a not-for-profit youth development organization, which runs summer day and residential camp programs for children, including children with medical conditions. It also runs a 5 hour program on Saturdays for children with disabilities aged 4 to 12 along with their siblings, to provide respite for caregivers.

Enclosure II

Comments from the Department of Health and Human Services



DEPARTMENT OF HEALTH & HUMAN SERVICES

OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

OCT 5 2010

Debra Draper
Director, Health Care
U.S. Government Accountability Office
441 G Street N.W.
Washington, DC 20548

Dear Ms. Draper:

Attached are comments on the U.S. Government Accountability Office's (GAO) correspondence entitled: "Respite Care: Grants and Cooperative Agreements Awarded to Implement the Lifespan Respite Care Act" (GAO 11-28R).

The Department appreciates the opportunity to review this correspondence before its publication.

Sincerely,

Jim R. Esquea
Assistant Secretary for Legislation

Attachment

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S (GAO) DRAFT CORRESPONDENCE ENTITLED, "RESPITE CARE: GRANTS AND COOPERATIVE AGREEMENTS AWARDED TO IMPLEMENT THE LIFESPAN RESPITE CARE ACT "(GAO-11-28R)

The Department appreciates the opportunity to review and comment on this draft correspondence.

Family caregivers perform a broad range of activities that include assisting care recipients with routine daily tasks to more complex interventions like medication management and wound care. The demand placed on family caregivers often exacts physical, emotional and financial challenges on them. Fortunately, respite services are available to provide temporary relief from caregiving responsibilities and enables caregivers to rest and recharge, thus ensuring their capacity to provide care longer and prevent unnecessary and premature institutionalization for their loved ones.

The Lifespan Respite Care Act of 2006 is designed to improve the delivery and quality of respite services across age and disability groups by establishing coordinated systems of respite care services. Since 2009, the Administration on Aging (AoA) has worked to implement the requirements of the Act in an effort to enable states to build more efficient and effective respite care delivery systems.

The information in this draft correspondence is clear and concise, highlighting the efforts of HHS and AoA to implement the program according to Statute and Congressional Intent. The summary tables provide a clear and easy reference to the Project Objectives and Planned Activities for the states that received grants in FY 2009 and FY 2010.

Given the relative newness of the Lifespan Respite Care Program, this document provides an excellent overview of HHS implementation efforts to date and is a useful resource for anyone interested in learning more about the development of respite care systems. It will help to highlight the critical role family caregivers play in the system of long term services and supports in the United States and the importance of efficient and effective respite care systems in helping caregivers continue their important work.

GAO Contact and Staff Acknowledgments

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