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**National Respite Coalition**  
**Statement for HELP Committee Staff on Caregiving Issues**  
**September 9, 2011**

Thank you for the opportunity to submit additional comments on the reauthorization of the Lifespan Respite Care Program. I am representing the National Respite Coalition (NRC), as well as the undersigned 28 national organizations. The National Respite Coalition is a grassroots membership organization representing family caregivers, respite providers, state respite coalitions, and other national, state, and local agencies. The NRC also facilitates the Lifespan Respite Task Force, a coalition of over 70 national organizations supporting the Lifespan Respite Program.

***Background and Program Status***

The LRCP is not part of the Older Americans Act, but as a crucial component of any comprehensive strategy to assist family caregivers, we are very grateful to be part of the discussion today. The Lifespan Respite Care Program was authorized under a new Title XXIX to the Public Health Service Act when enacted by Congress in 2006 (P.L. 109-442), but it received no funding at all until FY 2009. The program is authorized at \$94.8 million for FY 11, but has never received more than \$2.5 million in any of the fiscal years 2009-2011. For FY 12, the President has recommended \$10 million as part of the Administration's Caregiver Initiative.

Despite the limited funding, 30 states have successfully competed for Lifespan Respite Grants awarded by the Administration on Aging. Each state grant is \$180,000-\$200,000 over three years – or about \$60,000/year. With these limited funds, states are expected to build state Lifespan Respite Systems that will improve access to respite for all family caregivers. They

are also required to provide planned and emergency respite services, train and recruit respite workers and volunteers, and train and assist family caregivers to find and pay for respite.

### ***Relationship to Other Caregiver Programs***

The *National Family Caregiver Support Program* (NFCSP), Title III-E of the Older Americans Act, and the newly enacted *Program of Comprehensive Assistance for Family Caregivers* authorized by the Caregivers and Veterans Omnibus Health Services Act of 2010, P.L. 111-163, are important in their own right for the breadth and concentration of essential support they provide to family caregivers beyond respite. However, because they fund respite for categories of eligible individuals, these programs and others are important building blocks for comprehensive, coordinated Lifespan Respite systems. Full support for the NFCSP and other disparate funding streams for respite is critical so that Lifespan Respite systems can focus their funding on the unserved and on improving the efficiency, capacity, accessibility, and quality of available respite services for everyone.

The goals of Lifespan Respite systems are to maximize and more efficiently use existing resources, leverage new public and private resources, and coordinate the disparate funding streams and services that are currently fragmented by age, disability, or other restrictive eligibility criteria so that families no longer perceive service barriers. Lifespan Respite does not duplicate other efforts – it coordinates and enhances them. It is the only federal program ***focused*** on respite, the only federal program authorized to build respite capacity through provider training and recruitment, the only federal program coordinating respite across agencies and funding streams, and the only federal program permitted to use funds for the start up of new programs and services to address the huge gaps in respite service delivery.

## ***The Need for Respite***

And there are huge gaps for every age and condition. Nearly 90% of family caregivers, including 81% of family caregivers providing care to someone under age 18, are not receiving respite. While respite is in critically short supply for the aging population, especially the frail elderly and those with severe Alzheimer's and other dementias, it is critical to note that a majority (56%) of the individuals being cared for by the nation's family caregivers are under age 75 and 28% are under age 50. People ages 18 to 60 with multiple sclerosis, ALS, spinal cord or traumatic brain injuries, mental health conditions, and even cancer, are least likely to qualify for any public or private respite funding, but their caregivers are still at risk of poor physical and emotional consequences. Adults with developmental disabilities who live at home with their aging caregivers are also increasingly at risk of out-of-home placements. A recent study from The Arc found that significantly more than 75% of family caregivers caring for adult children with developmental disabilities could not find respite services.

According to a 2009 National Alliance for Caregiving Survey, 85% of veterans had not received respite services from the US Department of Veterans' Affairs (VA) or any other community organization within the past twelve months. The new VA Caregiver initiative that is underway will make a huge difference in supporting family caregivers, especially those caring for veterans since 9/11, but even the VA is worried about where and how they will find appropriate and accessible respite providers that will provide services families need. Local VA caregiver coordinators are beginning to collaborate with State Lifespan Respite programs to assist them in their efforts and the VA and AoA are exploring more formal relationships.

### ***How is Lifespan Respite Program Making a Difference?***

Even though Lifespan Respite grantees are in their infancy, they are undertaking innovative activities with their extremely limited funds such as:

- In TN and RI, the Lifespan Respite program is building respite capacity by expanding volunteer networks of respite providers by recruiting University students or Senior Corps volunteers or expanding the national TimeBanks model for establishing voluntary family cooperative respite strategies.
- In Texas, the Lifespan Respite program has established a statewide Respite Coordination Center and they are gathering input from family caregivers and providers in every corner of the state.
- In NC, SC, and AL, the state respite coalition and the Lifespan Respite programs are partnering in new and exciting ways with the otherwise untapped faith community to provide respite, especially in rural areas.
- The North Carolina Lifespan Respite Program has challenged each of its 100 counties to come up with a strategy, no matter how great or how small, to improve respite service delivery locally.
- In NH, important new training protocols are being developed to expand the pool of respite providers to work with teens and older individuals with mental health conditions or other groups where respite is in short supply.
- In IL and AZ, the state grantees and their partners are working with child and adult protective services to ensure respite is available on an emergency basis for the most vulnerable families.

Across the board, states are building respite registries and “no wrong door systems” in collaboration with state respite coalitions and Aging and Disability Resource Centers to help family caregivers access respite and respite funding sources. OK, AL, TN and others are using Lifespan Respite grants to expand or implement participant-directed respite so that family caregivers have greater control over the type and quality of the respite they select. Regardless of which state agency takes the lead, they are not alone. All state grantees secure commitments from partnering state agencies to share information and coordinate resources to build a seamless Lifespan Respite system for accessing respite.

***Why is respite so important?***

Other than direct financial assistance, respite is the service most frequently requested by family caregivers. Most caregivers freely and willingly provide this care out of love and commitment, but often at great cost to themselves physically, emotionally, and financially. One in five caregivers report that they are in fair or poor health; 43% report having a chronic health condition that requires ongoing medical care, putting themselves at great risk and jeopardizing their ability to provide continued care to their dependent loved ones. An estimated 46%-59% of family caregivers are clinically depressed. An often-cited medical study found that participants who were providing care for an elderly individual with a disability and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls.

Respite is certainly not the only component of a system of supports family caregivers so desperately need, but it can be an important bridge to introducing families to more comprehensive and needed supports. Respite has been shown to improve a family caregiver’s health and well-being if provided early and frequently in the caregiving experience. For families

who are under severe stress from continuous caregiving, respite has been shown to save marriages and keep families intact and can even help in preventing abuse or neglect. Respite can help a family avoid or delay much more costly out-of-home placements like foster care or nursing homes. Delaying placement of even one individual with Alzheimer's in a nursing home or 1 or 2 months can save Medicaid and the family thousands of dollars. For a caregiver providing intense and exhausting care 24 hours a day, 7 days a week, 365 days a year, an occasional short break can literally be a lifesaver.

### ***Reauthorization Request***

To help inform the reauthorization process, the US Administration on Aging (AoA) solicited input from interested individuals and organizations. All of the 23 responders indicated strong support for the program and respite services in general. Five respondents urged Congress to make no changes to the Act, including retaining current statutory language and intent stipulating that all populations are to be served and that no phase-in of population groups be permitted. Four responders specifically indicated that the mandatory provisions in the law that focus on serving the broadest age and disability spectrum should be retained. In addition, it was requested these provisions continue to be required at the outset of grant activities and that programs develop on a statewide basis from the beginning.

Three responders expressed support for the continued strong roles and functions of the stateside Respite Coalitions and the continued requirement of the memorandum of agreement between the Coalition and the Lead Agency. Such a memorandum provides assurances to constituents, members, and stakeholders of their participation in planning and implementation

of the Program and ensures respite expertise and caregiver input across the age and disability spectrum.

Four responders felt strongly that the Lifespan Respite Care Program should not be folded or consolidated into the Older Americans Act or other federal programs. The Act contains provisions for building respite capacity and provides for the development of planned and emergency respite; the recruitment and training of respite providers; and improving quality, collaboration, coordination and access to respite for all ages. Such provisions make the Act a unique and a critical component of overall long term services and supports system. Finally, as the statute is currently written, states have considerable flexibility and local control in implementing Lifespan Respite Care Programs. Five responders felt that such flexibility and local control should be retained in the reauthorization of the Act as such qualities permit states to determine the best approaches for developing respite systems that respond to the unique needs within their own communities.

The Lifespan Respite Task Force supports these findings collected by AoA. The program is so new, that we do not have enough information to know if or how the program should be changed in any way. To allow the program to be fully evaluated before any changes are considered, and to help ensure that the program will be funded in a timely way, the Task Force recommends an expedited reauthorization with no changes to current law. Thank you for consideration of our input. If you would like more information, please contact me at 703-256-2084 or via email at [jbkagan@verizon.net](mailto:jbkagan@verizon.net).

Respectfully,  
Alzheimer's Foundation of America  
American Association for Geriatric Psychiatry  
American Network of Community Options and Resources

Association of University Centers on Disabilities  
Bazelon Center for Mental Health Law  
Brain Injury Association of America  
Christopher & Dana Reeve Foundation  
Easter Seals  
Epilepsy Foundation  
Family Caregiver Alliance  
Family Voices  
Mental Health America  
National Alliance for Caregiving  
National Association of Area Agencies on Aging (n4a)  
National Association of State Directors of Special Education  
National Association for Home Care & Hospice  
National Association of State Head Injury Administrators  
National Down Syndrome Congress  
National Down Syndrome Society  
National Family Caregiver Association  
National MPS Society  
National Multiple Sclerosis Society  
OWL-The Voice of Midlife and Older Women  
Paralyzed Veterans of America  
Rosalynn Carter Institute for Caregiving  
The ALS Association  
The Arc  
United Spinal Association