Thank you for the opportunity to discuss reauthorization of the Older Americans Act programs. I am representing the National Respite Coalition (NRC), which 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.

**What is Respite?**

Respite is temporary relief for family caregivers who provide continuous care to aging family members or friends or others with disabling or chronic conditions. It probably first developed informally in the late 1950s and 60s with the first wave of deinstitutionalization. California was among the first states to enact legislation authorizing respite for individuals with developmental disabilities. Congress enacted a small respite program for children in the mid 1980s about the same time Medicaid home and community based waivers, which also fund respite, were developing. The Supreme Court’s Olmstead Decision in 1999 spurred federal and state action to help ensure that individuals with disabilities could live at home and in the community. Federal Real Systems Change grants funded state efforts to expand respite for children and adults. But in 2000, the NFCSP was the first federal legislation enacted to recognize family caregivers in their own right.
Background and Program Status

Because our organization focuses on respite for family caregivers of all ages, I am going to focus on the importance of respite in Title III E, the National Family Caregiver Support Program. As you know, respite is one of several core activities funded by this program. In fiscal year 2008, the National Family Caregiver Support Program (NFCSP) provided respite care services to more than 73,000 caregivers with 9.8 million hours of temporary relief— at home, or in an adult day care or institutional setting – from their caregiving responsibilities. The Native American Caregiver Support Program provided respite to 4761 caregivers.¹ An evaluation of the program found that:

- 77 percent of caregivers receiving services under NFCSP report that services definitely enabled them to provide care longer than otherwise would have been possible, and 77 percent reported that the services have “helped a lot”;
- 89 percent of caregivers reported that services helped them to be a better caregiver;
- Nearly half the caregivers of nursing home eligible care recipients indicated that the care recipient would be unable to remain at home without the support services offered by the NFCSP.

The Need for Respite

Despite the success of the NFCSP in reaching the aging population with family caregiver supports, nearly 90% of family caregivers are still not receiving respite. Respite remains in critically short supply for the aging population, especially the frail elderly and those with severe

Alzheimer’s and other dementias. However, 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 (National Alliance for Caregiving, 2010). 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. Since many of these conditions, such as MS or ALS can have early onset, and others are the result of accident or unexpected illnesses, they can happen any time in adulthood. Adults with developmental disabilities who live at home with their aging caregivers are also increasingly at risk of out-of-home placements. An estimated 4.8 million people with intellectual and developmental disabilities (I/DD) live in the US. The vast majority (60%) live at home with family caregivers. If the caregivers are parents, they do not qualify for the National Family Caregiver Support Program (NFCSP). 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 more appropriate and accessible respite providers and respite options that will provide services families want and need.
Eligibility for respite and other family caregiver supports was expanded in the 2006 reauthorization of the NFCSP. But there are still huge gaps in service delivery.

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 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.

Respite Barriers

A Scorecard on how states were doing in providing long-term services and supports, including supports to family caregivers, was released yesterday in a report prepared by AARP and funded by the SCAN Foundation and the Commonwealth Fund. Some states reported significant percentages of family caregivers who say they are getting all the supports they need, but that is not the case in most states. Barriers to respite include cost, lack of well-qualified trained respite providers, too few respite programs and options that meet family caregiver or care recipient needs, not feeling comfortable asking for help or knowing where to go to get help, not identifying as a caregiver, and facing complicated and fragmented service delivery systems that are difficult to navigate.

The National Family Caregiver Support Program (NFCSP), Title III-E of the Older Americans Act is important for the breadth and concentration of essential supports they provide to family caregivers beyond just respite. With so many family caregivers still not accessing respite, and with the aging of the baby boom generation, funding for the NFCSP must rise to meet the need.

Legislative Recommendations for Improving Respite in the Older Americans Act:

• Strengthen the National Family Caregiver Support program by increasing its authorization to $250 million per year.
• Clarify that older parents of adult children with disabilities are eligible for NFCSP.

• To address the critical shortage of respite providers, in appropriate sections of the Older Americans Act, develop new roles and opportunities for older volunteers to provide respite and other services to vulnerable seniors, children and their families;

However, respite solutions must transcend those addressed by the NFCSP. NFCSP is one of many important components to a coordinated, quality respite system in the states that will make respite accessible to all family caregivers in need.

Finally, to coordinate all the disparate funding streams for respite and eliminate the barriers to respite, to improve respite capacity and quality, reauthorize the Lifespan Respite Care Act, which also expires this year. The LRCP is not part of the Older Americans Act, but is a crucial, overarching component of any comprehensive strategy to assist family caregivers. The Lifespan Respite Task Force supports the findings collected from the field by the Administration on Aging to reauthorize the program with no changes to current law. 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 National Respite Coalitions and members of the Lifespan Respite Task Force recommend an expedited reauthorization with no changes to current law.

Thank you for consideration of our input. If you would like more information, please contact Jill Kagan at NRC, 703-256-2084 or at jbkagan@verizon.net.