

April 29, 2013

The Honorable Jack Kingston  
Chairman  
Appropriations Subcommittee on Labor,  
Health and Human Services, and Education  
2358-B Rayburn House Office Bldg.  
Washington, DC 20515

The Honorable Rosa DeLauro  
Ranking Member  
Appropriations Subcommittee on Labor,  
Health and Human Services, and Education  
1016 Longworth House Office Bldg.  
Washington, DC 20515

Dear Chairman Kingston and Ranking Member DeLauro:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge necessary funding in the FY 2014 Labor/HHS/Education Appropriations bill for respite and other critical family support programs that provide the safety net for family caregivers across the lifespan. We are especially aware of the fiscal constraints facing the nation and we make our requests in light of the current budget limitations. First, we are requesting **\$2.5 million for the Lifespan Respite Care Program**, which represents level funding from FY2012. We are also seeking support for the **National Family Caregiver Support Program (\$154 million)**; the **Native American Caregiver Support Program (\$6 million)**, and **Title II Family Support Program** under the Developmental Disabilities Act.

In 2011, the first baby boomer turned 65. Each day, another 10,000 turn 65 and this trend will continue for the next two decades. While this is a growing issue and must be addressed immediately for the health and well being of the nation's families, 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. Family caregiving is not just an aging issue, but also a lifespan issue for the majority of the nation's families.

Respite is out of reach for the vast majority of family caregivers caring for adults or children with disabilities or chronic conditions. Close to 90% of the nation's 65 million family caregivers do not receive any respite. For those family caregivers caring for someone with early Alzheimer's, adults with developmental disabilities living at home with aging parents, individuals with MS, ALS, spinal cord or traumatic brain injury, respite is especially elusive. Families caring for children and teens with autism, physical disabilities or serious emotional disturbance also can't find or afford respite. A 2011 survey of nearly 5,000 caregivers of individuals with intellectual and developmental disabilities conducted by The Arc found that more than 75% reported problems finding respite.

Respite is one of the most frequently requested services among family caregivers and can help save dollars by avoiding or delaying out-of-home placements or hospitalizations. In a survey of family caregivers of individuals with Multiple Sclerosis, two-thirds said that respite care would help them keep their loved ones at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75%.

Research has documented the cost savings resulting from respite services. Researchers at the University of Pennsylvania studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every \$1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization.

Lifespan Respite systems, which maximize existing resources, require that respite become more accessible and available to all family caregivers. As importantly, Lifespan Respite systems help build respite capacity and improve quality by requiring states to focus on respite provider/volunteer training and recruitment, funding of start-up of all models of respite delivery, and affordability issues for the family caregivers who currently are not eligible for any existing federal or state programs that support respite.

The Lifespan Respite Care program is significantly underfunded at \$2.5 million. However, by investing even this small amount in Lifespan Respite and other family and caregiver supports, the goal of avoiding or delaying more costly institutional care, hospitalizations and emergency room use, can be reached. More than at any other time, when Medicaid is severely threatened, any effort that can help reduce Medicaid expenditures for long-term services and supports and preserve the program's integrity, should be on the front burner.

NFCSP was the first federal program to recognize the needs of the nation's family caregivers who provide the backbone of long-term services and supports. NFCSP not only funds respite, but individual counseling, support groups, and caregiver training for family caregivers, primarily for those who are caring for the aging population and for individuals of any age with Alzheimer's or other dementias. It also provides limited supports for grandparents and other older relatives to provide care for adults and children with disabilities. The Family Support Program authorized under Title II of the Developmental Disabilities Act has never been adequately funded and families of individuals with developmental disabilities struggle without necessary support and worry about their children's future.

We strongly urge you to fund Lifespan Respite at the very modest request of \$2.5 million and to also ensure funding for the National Family Caregiver Support Program (\$154 million) and the Native American Caregiver Support Program (\$6 million), and Title II Family Support. More than 65 million family caregivers in the US are counting on you this year.

Sincerely,

ACCSES  
Alzheimer's Foundation of America  
American Association for Geriatric Psychiatry  
American Association of People with Disabilities  
American Association on Health and Disability  
American Dance Therapy Association

American Music Therapy Association  
American Psychological Association  
Association of University Centers on Disabilities  
Autism National Committee  
Bazelon Center for Mental Health Law  
Caregiver Action Network  
Christopher & Dana Reeve Foundation  
CWLA  
Division for Early Childhood of the Council for Exceptional Children (DEC)  
Easter Seals  
Family Voices, Inc.  
Generations United  
Huntington's Disease Society of America  
IDEA Infant Toddler Coordinators Association (ITCA)  
Lupus Foundation of America  
National Alliance for Caregiving  
National Association of Area Agencies on Aging (n4a)  
National Association for Home Care & Hospice  
National Association of Mothers' Centers  
National Association of State Directors of Developmental Disabilities Services  
National Association of State Directors of Special Education  
National Association of State Head Injury Administrators  
National Association of States United for Aging and Disabilities  
National Center on Caregiving, Family Caregiver Alliance  
National Child Abuse Coalition  
National Committee to Preserve Social Security and Medicare  
National Council on Aging  
National Association of Councils on Developmental Disabilities  
National Down Syndrome Congress  
National MPS Society  
National Multiple Sclerosis Society  
National Respite Coalition  
OWL-The Voice of Midlife and Older Women  
Paralyzed Veterans of America  
Parkinson's Action Network  
The ALS Association  
The Arc  
United Spinal Association  
Well Spouse Association

cc: Kathy Greenlee, Administrator, Administration for Community Living