

May 2, 2012

The Honorable Tom Harkin  
Chair  
Subcommittee on Labor, HHS, and Education  
Committee on Appropriations  
U.S. Senate  
Washington, D.C. 20510

The Honorable Shelby  
Ranking Member  
Subcommittee on Labor, HHS, and Education  
Committee on Appropriations  
U.S. Senate  
Washington, D.C. 20510

Dear Chairman Harkin and Ranking Member Shelby:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge necessary funding in the FY 2013 Labor/HHS/Education Appropriations bill for respite and other critical support programs that provide the safety net for family caregivers across the lifespan. First, we are requesting **\$5 million for the Lifespan Respite Care Program**. Given the serious fiscal constraints facing the nation, this request is reduced significantly from prior years' requests. We are also seeking support for the **National Family Caregiver Support Program (\$154 million); and the Native American Caregiver Support Program (\$6 million)**.

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. The aging population needing long term care is expected to reach 27 million in 2050. Meanwhile the pool of younger adults (ages 20 to 64) to give care will shrink—from a ratio of 4.6:1 in 2010, to 2.6:1 in 2050. 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 all family caregivers caring for adults or children. 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 can't find or afford respite either. 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.

Families of wounded warriors – those military personnel who have returned from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating physical and mental health conditions - are at risk for limited access to respite. The new VA Family Caregiver Program is providing important comprehensive supports for family caregivers of veterans, including expanded respite options. But appropriate services and qualified providers for this population are still in short supply. According to a 2010 National Alliance for Caregiving Study, only 15% of veterans had received respite services from the VA or some other community organization within the past twelve months. The VA is looking to Lifespan Respite Programs to help find the respite providers and services to increase respite use for this population.

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 recent survey of family

caregivers of individuals with Multiple Sclerosis, two-thirds say 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%. A recent study documented the cost benefits of respite, specifically for Medicaid. 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.

In light of this tremendous need and the benefits respite can accrue, the Lifespan Respite Care program is significantly underfunded at \$2.5 million. By investing in Lifespan Respite, states will be able to implement comprehensive and coordinated systems of respite for family caregivers across age and disability categories, with the goal of saving billions of dollars in more costly institutional care, hospitalizations and emergency room use, as well as state administrative costs. 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.

These 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.

Long-overdue full funding for the NFCSP is critical also. It 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 other critical supports 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.

We strongly urge you to fund Lifespan Respite at the very modest request of \$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). More than 65 million family caregivers in the US are counting on you this year.

Sincerely,

American Association for Geriatric Psychiatry  
American Association on Health and Disability  
American Psychological Association  
Association of University Centers on Disabilities  
Autism National Committee  
Bazelon Center for Mental Health Law  
Brain Injury Association of America  
Christopher & Dana Reeve Foundation  
Division for Early Childhood of the Council for Exceptional Children (DEC)  
Easter Seals  
Family Caregiver Alliance

Family Voices

IDEA Infant Toddler Coordinators Association (ITCA)  
National Alliance for Caregiving  
National Domestic Workers Alliance  
National Association for Home Care & Hospice  
National Association of Area Agencies on Aging (n4a)  
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 Council on Aging  
National Down Syndrome Congress  
National Family Caregivers Association  
National Federation of Families for Children's Mental Health  
National MPS Society  
National Multiple Sclerosis Society  
National Respite Coalition  
OWL-The Voice of Midlife and Older Women  
Paralyzed Veterans of America  
Rosalynn Carter Institute for Caregiving  
The Arc  
United Cerebral Palsy  
United Spinal Association  
Well Spouse(tm) Association

cc: Assistant Secretary on Aging Kathy Greenlee  
Kareem Dale, Special Assistant to the President  
Brian Levine, Office of the Vice President