

May 10, 2010

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

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

Dear Chairman Harkin and Ranking Member Cochran:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge full funding in the FY 2011 Labor/HHS/Education Appropriations bill for respite and other critical support programs that provide the safety net for family caregivers across the lifespan: **The Lifespan Respite Care Program (\$94.8 million); the National Family Caregiver Support Program (\$202 million) and the Native American Caregiver Support Program (\$8 million);** and Title I, Section 101, **Assistance and Support Services for Caregivers of the newly enacted Caregiver and Veterans Omnibus Health Care Act (\$60 million).**

This request is in line with President Obama's recent Middle Class Initiative. A prominent component of the initiative includes increased funding for the National Family Caregiver Support Program (NFCSP) by \$50 million and the Lifespan Respite Program by \$2.5 million. We commend the Administration for elevating the needs of the nation's family caregivers as an immediate budget priority for FY 2011. However, the President's recommendations focus on caregiving of the aging population. 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.

The Lifespan Respite Care program is significantly underfunded at \$2.5 million. This represents less than \$0.18 per family caregiver in the 12 states currently funded by the program. By fully funding 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, as well as state administrative costs. 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. Without expansion of Lifespan Respite systems, individuals with ALS, MS, spinal cord injuries, traumatic brain injuries, and mental health conditions, as well as, parents of adults with developmental disabilities, and children with emotional or physical disabilities will still be left out in the cold.

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 care. 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.

The new supports for veterans' caregivers address a growing need as well. Families of the wounded warriors – those military personnel returning 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. Veterans from other eras who have not received appropriate or available respite will also benefit from these new provisions.

NFCSP and the newly enacted caregiver supports for veterans are important in their own right for the breadth and concentration of support they can provide to family caregivers. Because they fund respite for certain categories of eligible individuals, the NFCSP and the caregivers for veterans support provisions also provide important building blocks for comprehensive, coordinated Lifespan Respite systems. Full funding for the NFCSP and other disparate funding streams for respite is critical so that Lifespan Respite systems can focus their funding on the underserved and on improving the efficiency, capacity, accessibility and quality of available respite services for everyone.

We strongly support the President's initiative to garner support for family caregivers, but we urge you to make sure the majority of family caregivers are not left out. Please fully fund the Lifespan Respite Care Program (\$94.8 million); the National Family Caregiver Support Program (\$202 million) and the Native American Caregiver Support Program (\$8 million); and Title I, Section 101, Assistance and Support Services for Caregivers of the newly enacted Caregiver and Veterans Omnibus Health Care Act (\$60 million). More than 65 million family caregivers in the US are counting on you this year.

Sincerely,

Alzheimer's Foundation of America
American Association for Geriatric Psychiatry
American Association of Pastoral Counselors
American Association of People with Disabilities
American Music Therapy Association
American Psychological Association
Association of University Centers on Disabilities
Autism Society
Bazelon Center for Mental Health Law
Brain Injury Association of America
Caregiver Media Group

Easter Seals
Epilepsy Foundation
Family Voices
Generations United
National Alliance of Children's Trust and Prevention Funds
National Alliance for Caregiving
National Association for Home Care & Hospice
National Association of Councils on Developmental Disabilities
National Association of Social Workers
National Association of State Directors of Special Education
National Association of State Head Injury Administrators
National Center on Caregiving, Family Caregiver Alliance
National Child Abuse Coalition
National Disability Rights Network
National Down Syndrome Congress
National Down Syndrome Society
National Family Caregivers Association
National Health Council
National Hospice and Palliative Care Association
National MPS Society
National Multiple Sclerosis Society
National Partnership for Women & Families
National Rehabilitation Association
National Respite Coalition
National Spinal Cord Injury Association
OWL - The Voice of Midlife and Older Women
Paralyzed Veterans of America
Rosalynn Carter Institute for Caregiving
TASH
The ALS Association
The Arc
United Cerebral Palsy
United Spinal Association
Well Spouse™ Association

cc: Assistant Secretary on Aging Kathy Greenlee
Jeffrey Crowley Director, Office of National AIDS Policy and Senior Advisor on
Disability Policy, The White House