

July 6, 2011

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

The Honorable Richard 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 2012 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 **\$50 million for the Lifespan Respite Care Program**. Given the serious fiscal constraints facing the nation, this request has been reduced by one-half below the previous fiscal year's authorized and our requested amount, yet sufficient to begin to address family caregiver needs equitably across the lifespan. We are also seeking support for the **National Family Caregiver Support Program (\$192 million); the Native American Caregiver Support Program (\$8 million); the Caregivers and Veterans Omnibus Health Care Program**, and the **Title II Family Support Program** under the Developmental Disabilities Act.

This request is in line with President Obama's Caregiver Initiative, included in the Administration's FY 12 Budget Proposal, to expand help to families and seniors so that caregivers can better manage their multiple responsibilities. Prominent components of the President's initiative include increased funding for the **National Family Caregiver Support Program (NFCSP) by \$38 million to the total of \$192 million and the Lifespan Respite Program by \$7.5 million to a total of \$10 million**. He also recommended \$202 million for the Caregivers and Veterans Omnibus Health Care Program, but recommended a \$6 million cut in the Programs of National Significance in the Developmental Disabilities Act, which will likely mean a cut in the Family Support Program. We commend the Administration for elevating the needs of the nation's family caregivers as an immediate budget priority for FY 2012. However, the President's recommendations still 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.

Currently, the Lifespan Respite Care program is significantly underfunded at \$2.5 million. Close to 90% of the nation's 65 million family caregivers do not receive any respite, including 81% of family caregivers providing care to someone under age 18 (National Alliance for Caregiving and AARP, 2009). By adequately 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. 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. 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. A new 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.

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 authorized for veterans' caregivers address a growing need as well. Families of 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. 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. Veterans from other eras who have not received appropriate or available respite will also benefit from these new provisions as well as from the Lifespan Respite Care Program.

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 beyond just respite. However, because they fund respite for 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 unserved 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 fund Lifespan Respite adequately to ensure the majority of family caregivers are not left out. **Please fund the Lifespan Respite Care Program at \$50 million -- this represents our request reduced by half from last year and half the authorized amount;** the National Family Caregiver Support Program (\$192 million) and the Native American Caregiver Support Program (\$8 million); the Caregivers and Veterans Omnibus Health Care Act, and the Title II Family Support Program under the Developmental Disabilities Act. More than 65 million family caregivers in the US are counting on you this year.

Sincerely,

Alliance for Retired Americans
Alzheimer's Foundation of America
American Association of Pastoral Counselors
American Association for Geriatric Psychiatry
American Association on Intellectual and Developmental Disabilities
American Dance Therapy Association
American Psychological Association
Association of University Centers on Disabilities
Autism National Committee
Autism Society
Bazelon Center for Mental Health Law
Brain Injury Association of America
Christopher and Dana Reeve Foundation
Disability Rights Education and Defense Fund
Easter Seals
Family Caregiver Alliance
Family Voices
Generations United
Huntington's Disease Society of America
Mental Health America
National Alliance for Caregiving
National Association for Home Care & Hospice
National Association of Social Workers
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 Council on Independent Living
National Down Syndrome Congress
National Down Syndrome Society
National Family Caregivers Association
National Federation of Families for Children's Mental Health
National Multiple Sclerosis Society
National MPS Society
National Respite Coalition
OWL-The Voice of Midlife and Older Women
Paralyzed Veterans of America
Prader-Willi Syndrome Association (USA)
Rosalynn Carter Institute for Caregiving
TASH
The ALS Association
The Arc of the United States
United Cerebral Palsy
United Spinal Association

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