

April 4, 2008

The Honorable David Obey
Chair
Subcommittee on Labor, HHS and Education
Committee on Appropriations
U.S. House of Representatives
Washington, D.C. 20515

The Honorable James T. Walsh
Ranking Member
Subcommittee on Labor, HHS and Education
Committee on Appropriations
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Obey and Ranking Member Walsh:

We, the undersigned national organizations, are writing to request that the Subcommittee include funding for the Lifespan Respite Care Act (PL 109-442) in the FY 09 Labor, HHS and Education Appropriations bill at its modest authorized level of \$53.3 million. Despite its widely supported enactment in 2006, the program has not yet been funded. We join the 26 Members of Congress who, along with Rep. Langevin (D-RI) and Rep. Ferguson (R-NJ), recently sent a letter to the Subcommittee making this same request. The Senate Budget Resolution also reserves \$53 million in the Department of Health and Human Services Account for Lifespan Respite.

The Lifespan Respite Care Act authorizes competitive grants to Aging and Disability Resource Centers in collaboration with a public or private non-profit state respite coalition or organization to make quality respite available and accessible to family caregivers regardless of age or disability. The law allows grantees to identify, coordinate and build on federal, state and local respite resources and funding streams, and would help support, expand and streamline planned and emergency respite, provider recruitment and training, and caregiver training.

The nation's estimated 50 million family caregivers provide 80% of long-term care. Respite, the most frequently requested family support service, has been shown to provide family caregivers with the relief necessary to maintain their own health, bolster family stability, keep marriages intact, and avoid or delay more costly nursing home or foster care placements. We know what to do. The Act is based on model State Lifespan Respite Systems in Wisconsin, as well as in Oregon, Nebraska, and Oklahoma. These systems provide easy access to an array of affordable, quality respite services; ensure flexibility to meet diverse needs; and assist with locating, training, and paying respite providers. A new program will soon be up and running in Arizona, as well.

For families and individuals who may not qualify for any other public or private respite funding streams, including children with severe disabilities, teens with serious emotional conditions, and adults with Multiple Sclerosis, ALS, traumatic brain injury, spinal cord injuries, cancer, Alzheimer's and many other chronic conditions, these programs may be holding out the only helping hand.

In these times of serious budget constraints, the economic value that accrues from respite is exceptional. Delaying nursing home or institutional placement of just one individual with a chronic condition for several months can save Medicaid, private insurance, or the family thousands of dollars. The value of uncompensated family caregiving services to the U.S. economy is estimated at \$350 billion a year, more than twice what is spent nationwide on nursing homes and paid home care combined and comparable to Medicare spending in 2005. American

Businesses lose \$17.1 to \$33.6 billion annually in lost productivity costs related to caregiving responsibilities.

We urge you to provide the \$53.3 million authorized by law for Lifespan Respite programs in the FY 09 Labor, HHS, and Education appropriations bill and thank you for your ongoing leadership on this issue. The program has strong bipartisan support and the Act passed unanimously in both chambers in the 109th Congress. Send a message to the nation's family caregivers that we value their health and well-being and that help is on the way.

Sincerely,

AARP

Alzheimer's Association

Alzheimer's Foundation of America

American Academy of Neurology

American Association for Geriatric Psychiatry

American Association on Intellectual & Developmental Disabilities

American Association of People with Disabilities

American Health Care Association

American Music Therapy Association

American Network of Community Options and Resources

American Occupational Therapy Association

American Public Health Association

American Psychological Association

American Society on Aging

Association of University Centers on Disabilities

Autism National Committee

Autism Society of America

Bazelon Center for Mental Health Law

Brain Injury Association of America

Chronic Illness Coalition

Disability Rights Education and Defense Fund

Division for Early Childhood of the Council for Exceptional Children (DEC) and

Easter Seals

Epilepsy Foundation

Family Voices

Generations United

IDEA Infant Toddler Coordinators Association (ITCA)

Lutheran Services in America

National Alliance for Caregiving

National Alliance of Children's Trust and Prevention Funds

National Alliance on Mental Illness

National Association of Councils on Developmental Disabilities

National Association of County Behavioral Health and Developmental Disability Directors

National Association of Social Workers

National Association of State Directors of Special Education

National Association of State Head Injury Administrators
National Center for Assisted Living
National Center on Caregiving, Family Caregiver Alliance
National Child Abuse Coalition
National Council on Aging
National Down Syndrome Congress
National Down Syndrome Society
National Family Caregivers Association
National Foster Parent Association
National Health Council
National MPS Society
National Multiple Sclerosis Society
National Rehabilitation Association
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
Well Spouse Association

cc: Cheryl Smith
Steve Crane
Todd Adams
Derick Apt