

April 8, 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 state and local 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 Dept. 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. If you need more information, please don't hesitate to contact Jill Kagan, National Respite Coalition at 703-256-9578 or at jbkagan@verizon.net.

Sincerely,

Alabama Lifespan Respite Resource Network
Caring Congregations, Inc., Tuscaloosa, AL
United Cerebral Palsy of Huntsville and Tennessee Valley, Inc., AL
Arizona Center on Aging, University of Arizona
Arizona Health Care Association
Church & Society Ministry Team, Paradise Valley United Methodist Church, Phoenix, AZ
Arizona Interfaith Network, Phoenix, AZ
Arizona Institute for Public Life, Phoenix, AZ
Hospice of the Valley, Phoenix, AZ
Northern Arizona Interfaith Council, Flagstaff, AZ
Pima County Interfaith Council, Tucson, AZ
Protecting Arizona's Family Coalition (PAFCO)
Valley Interfaith Project, Phoenix, AZ
Yuma County Interfaith Council, Yuma, AZ
Advocates Needed Today, Inc, Little Rock, AR
Bay Respite Care, Vallejo, CA
California Respite Association
ComForcare Home Care, Los Angeles, CA
Family Caregiver Alliance, San Francisco, CA
St. Barnabas Senior Services & S. Mark Taper Fdn Adult Day Care Center, Los Angeles, CA
Elder Care Network of Larimer County, Family Connections Committee, Fort Collins, CO
Larimer County Office on Aging, Fort Collins, CO
Special Kids Special Families, Colorado Springs, CO
Connecticut Lifespan Respite Coalition
Epilepsy Foundation of Connecticut
DC Children's Trust Fund
Alzheimer's Community Care, West Palm Beach, FL
Alzheimer's Family Organization, New Port Richey, FL
Dementia Caregiver Resources, Inc., Largo, FL
Florida Respite Coalition
Friends Hope Adult Day Services, Corp, Jacksonville Beach, FL
Rampart Group Inc dba Senior Care of Brevard, Cocoa Beach, FL
Epilepsy Foundation of Idaho
Idaho Children's Trust Fund
Prevent Child Abuse Idaho

Diamonds in the Ruff Children's Society, Chicago , IL
Epilepsy Foundation of Greater Chicago, IL
Lifelink Home Care/Alzheimer's at Home, Bensenville, IL
Right At Home, Algonquin, IL
Agape Respite Care, Inc., Berne, IN
Brain Injury Association of Indiana
Iowa Respite and Crisis Care Coalition
Link Associates Respite, Des Moines, IA
Lutheran Services in Iowa
The Arc of Iowa
Families Together, Inc., Wichita, KS
Kansas Lifespan Respite Coalition
Respite Outreach Care for Kansans Organization, Inc.
Sedgwick County Developmental Disability Organization, Wichita, KS
The Consumer Advisory Council of the Human Development Institute – University of Kentucky,
University Center for Excellence in Developmental Disabilities, Lexington, KY
The Grandparent Connection, Vine Grove, KY
United Cerebral Palsy of Northeastern Maine, Bangor, ME
Maryland Respite Care Coalition
Epilepsy Foundation of Massachusetts
Area Agency on Aging 1-B, Southfield, MI
Community Respite Center, Jackson, MI
Michigan Office of Services to the Aging
ALS in the Heartland, Omaha, NE
Children's Respite Care Center. Omaha, NE
Nebraska Respite Coalition
South Central Town Hall Caregiver Coalition, Hastings, NE
Desert Regional Center, Las Vegas, NV
Give Me A Break, Inc., Las Vegas, NV
Brain Injury Association of New Hampshire
ACCSES New Jersey
Autism Family Services of New Jersey
Brain Injury Association of New Jersey
Caregivers of New Jersey
Center for Educational Advancement-Flemington, NJ
Epilepsy Foundation of New Jersey
Family Resource Network of New Jersey
Family Support Center of New Jersey
New Jersey Family Voices
New Jersey Statewide Parent Advocacy Network
New Jersey Lifespan Respite Coalition
Occupational Center of Union County, Roselle,NJ
Opportunity Project, Inc., Millburn, NJ
Alzheimer's Foundation of Staten Island, New York
Catholic Charities Caregivers Support Services, Albany, NY
Catholic Charities of the Diocese of Albany, NY
The Alzheimer's Day Program @ the Herricks Community Center, New Hyde Park, NY
Brain Injury Association of North Carolina

Chapel Hill Training-Outreach Project, Inc., Chapel Hill, NC
National Multiple Sclerosis Society, North Carolina Chapters
North Carolina Respite and Crisis Care Coalition
Oklahoma Respite Resource Network
Clatsop Community Action, Astoria, OR
Lifespan Respite Care Network for Lincoln County, Newport, OR
Malheur County Lifespan Respite, Ontario, OR
Oregon Lifespan Respite Program
The Arc of Jackson County, Medford, OR
Alliance for Community Respite Care, Pittsburgh, PA
Alzheimer's Association, Pennsylvania Public Policy Coalition
Frederick Mennonite Community, Frederick, PA
Pennsylvania Association of Rehabilitation Facilities
Pennsylvania Respite Coalition
Pennsylvania Chapters National Multiple Sclerosis Society
Phoebe Home, Allentown, PA
St. Mary's Family Respite Center, Philadelphia, PA
United Cerebral Palsy of Pennsylvania
Epilepsy Foundation of Rhode Island
Catawba Area Agency on Aging, Rock Hill, SC
Central Midlands Family Caregiver Support Program, Columbia, SC
Lowcountry Country Family Caregiver Support Program, Yemassee, SC
South Carolina Respite Coalition
Alzheimer's Association, Memphis, TN
American Parkinson Disease Association, Middle TN Chapter, Nashville, TN
Arms, Johnson City, TN
Brain Injury Association of Tennessee
Center for Independent Living of Middle Tennessee, Nashville, TN
Memphis Respite Voucher Program, Memphis, TN
Tennessee Disability Coalition
Tennessee Respite Coalition
Tennessee Voices for Children
The Guidance Center, Volunteer Behavior Health, Murfreesboro, TN
Upper Cumberland Development District Area Agency on Aging and Disability, Cookeville, TN
Brain Injury Association of Texas
Parent to Parent of Vermont/Family Voices of Vermont
Mary's Family, Orlean, VA
Virginia Partnership for People with Disabilities, Virginia Commonwealth University
Alzheimer's Society of Washington
Booth Gardner Parkinson's Care Center, Evergreen Healthcare, Kirkland, WA
Respite and Crisis Care Coalition of Washington (RCCCWA)
The Arc of King County, Seattle, WA
Brain Injury Association of Wisconsin
Epilepsy Foundation South Central Wisconsin
Epilepsy Foundation Southern Wisconsin
Family Respite Care Services, Inc., Janesville, WI
Lifespan Respite Care Northern Network, Ashland, WI
Lifespan Respite Network, Beaver Dam

Respite Care Association of Wisconsin, WI
United Cerebral Palsy of South Eastern Wisconsin, Milwaukee, WI

Guam

Family Caregiver Support Program, Social Work Program, University of Guam, Mangilao, Guam
Center for Independent Living of Guam (Tamuning, Guam 98931)
Guam Developmental Disabilities Council (Mangilao, Guam 96913)
Catholic Social Services, Inc. (Barrigada, Guam 96913)
Guma Mami' Inc. (Hagatna, Guam 96932)
Pacific Abundant Living Ministries (PALM), Inc. (Upper Tumon, Guam 96911)