

May 22, 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 state and local 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 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 National Family Caregiver Support Program 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 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 National Family Caregivers Support Program 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 make sure the majority of family caregivers is 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,

Alabama

Alabama Lifespan Respite Resource Network	Statewide
Alacare Home Health Services, inc.	Birmingham
The ALS Association Alabama Chapter	Huntsville
United Cerebral Palsy of Huntsville and Tennessee Valley, Inc.	Huntsville

Arizona

Arizona Lifespan Respite Care Network	Scottsdale
---------------------------------------	------------

Arkansas

UCP of Arkansas	Little Rock
California	
Alternative Home Care	Sherman Oaks
Association of CA Caregiver Resource Centers	Paradise
At Your Home Familycare	San Diego
Bay Respite Care	Vallejo
California Respite Association	Statewide
Channel Islands Social Services	Camarillo
ComForcare Services	Redwood City
Community Resource Services	Yuba City
Elder Options, Inc.	Placerville
Family Care Partnership	San Fernando
Family Support Services of the Bay Area	Oakland
Families United - Respite	Lakeport
Los Angeles Caregiver Resource Center	Los Angeles
Manos Home Care	Oakland
Pacific Homecare Services	Stockton
Respite, Inc.	San Luis Obispo
Shella Care Mgt. Services	Sun City
The Respite Inn	Concord
Tri-County Respite Care Service	Yuba City
United Cerebral Palsy/Los Angeles	Woodland Hills
United Cerebral Palsy	Stockton
Colorado	
Colorado Respite Coalition	Statewide
National Organization to End the Wait Lists	Parker
Connecticut	
Abilis	Greenwich
CT Autism Spectrum Resource Center, Inc.	Wallingford
CT FamilyTo Family Health Information Network	
CT Lifespan Respite Coalition	Statewide
FAVOR, Inc.	Rocky Hill
St. Vincent's Special Needs Services	Trumbull
Delaware	
CHEER, Inc	Georgetown
Children & Families First	Wilmington
Delaware Caregivers Support Coalition	Statewide
Delaware Respite	Smyrna DE
Home Helpers	Wilmington
Multiple Sclerosis Society, Delaware Chapter	Wilmington
State Council for Persons with Disabilities	Dover
Georgia	
Easter Seals Southern Georgia	Albany

Georgia Respite Coalition	Statewide
Hawaii	
Children's Disability Rights Education Association	Kalaheo
Illinois	
Illinois Respite Coalition	Statewide
UCP Land of Lincoln	Springfield
Indiana	
Indiana Respite Coalition	Berne
Iowa	
Carroll County for the Prevention of Child Abuse	Carroll
Iowa Respite Coalition	Statewide
The ALS Association, Iowa Chapter	Statewide
Kansas	
Area Agency on Aging	Manhattan
Kansas Lifespan Respite Coalition	Statewide
Rainbows United, Inc.	Wichita
Respite Outreach Care for Kansans Organization, Inc.	Wichita
Trinity In-Home Care	Lawrence
UCP of Kansas	Statewide
Wyandotte/Leavenworth Area Agency on Aging	Kansas City
Maine	
United Cerebral Palsy of Northeastern Maine	Bangor
Woodfords Family Services	Portland
Maryland	
Easter Seals Greater Washington Baltimore Region	Silver Spring
Maryland Dept. of Human Resources	Baltimore
Maryland Department of Disabilities	Baltimore
Maryland Respite Care Coalition	Statewide
The Arc of the Central Chesapeake Region	Annapolis
St. Mary's County Social Services	Leonardtwn
Massachusetts	
Care.com	Waltham
Comfort Keepers of the North shore	Beverly
Elder Services of the Merrimack Valley	Lawrence
Greater Lynn Senior Services	Lynn
House of Possibilities, Inc.	Easton
Independent Living Center of the North Shore and Cape Ann, Inc.	Salem
Kennedy-Donovan Center	Foxboro

MA Council for Home Care Aide Services	Statewide
Massachusetts Developmental Disabilities Council	Statewide
Massachusetts Executive Office of Elder Affairs	Statewide
MA Families Organizing for Change	Raynham
MA Respite Coalition/MA Department of Developmental Services	Statewide
Nurturing Nest Inn for Respite Care	Falmouth
Radius Healthcare & Pediatric Center @ Plymouth	Plymouth
Seven Hills Foundation	Worcester
Toward Independent Living and Learning	Dedham

Michigan

Chronic Illness Coalition	Statewide
Hope and Healing Foundation	Statewide
Tatanka Hoksila, the Buffalo Boy Foundation	Southfield
United Cerebral Palsy of Michigan	East Lansing

Minnesota

The Arc of Minnesota	Saint Paul
UCP of Central Minnesota	St. Cloud

Missouri

Center for Human Services	Sedalia
Community Living, Inc.	St. Peters
Developmental Services of Jefferson Co.	Mapaville
Friends of L'Arche St. Louis	St. Louis
Governor's Council on Disability	Jefferson City
Lutheran Senior Services	St. Louis
Missouri Association of Area Agencies on Aging	Jefferson City
Missouri Planning Council for Developmental Disabilities	Jefferson City
National MS Society	St. Louis
Oxford HealthCare and Hospice	Springfield
Ozark Center	Joplin
Rural Advocates for Independent Living	Kirksville
Southeast Missouri Area Agency on Aging	Cape Girardeau
St. Louis Arc	St. Louis
St. Louis Family Respite Coalition	St. Louis
The ALS Association, St. Louis Chapter	St. Louis
The ALS Association	Springfield
TouchPoint Autism Services	St. Louis
UCP Easter Seals Heartland	Manchester

Nebraska

Great Plains Chapter Alzheimer's Association	Kearney
Nebraska Respite Coalition	Statewide
UCP of Nebraska	Omaha

Nevada

BrightPath Adult Enrichment Center	Elko
Desert Regional Center	Las Vegas
Lifespan Respite Program	Carson City
Nevada Lifespan Respite Care Coalition	Statewide

New Jersey

Caregivers of New Jersey	Brick
Family Support Coalition of New Jersey	Mt. Laurel
Family Support Center of NJ	Manasquan
Lifespan Respite Coalition of New Jersey	Trenton

New York

A Special Touch Center, Inc.	Brooklyn
Catholic Charities Caregivers Support Services	Albany
Delhi County Legacy Corps	Delhi
EAC Senior Respite Program	Hempstead
Glen Cove Adult Day Program	Glen Cove
Jewish Association for Services for the Aged	Commack
St. Francis Social Adult Day Care	Syracuse
Statewide Caregiving & Respite Coalition of NY	Albany

North Carolina

Caring for Children, Inc.	Asheville
Central North Carolina Chapter, National MS Society	Greensboro
Chapel Hill Training-Outreach	Chapel Hill
Coastal Community Action Senior Companion Program	Newport
Easter Seals UCP of North Carolina and Virginia	Statewide
Family Based Foster Treatment Association North Carolina Chapter	Winston-Salem
Family Support Network of Greater Forsyth	Winston-Salem
Forgiven I Serve Him, Inc	Henderson
Jackson County Dept. on Aging	Sylva
Mid-East Commission Area Agency on Aging	Washington
NC Family Caregiver Support Program Association	Statewide
North Carolina Respite Care Coalition	Statewide
The ALS Association, NC Chapter	Statewide
The Children's Home	Winston-Salem
The Council on Aging of Buncombe County, Inc.	Ashville
The GEM Center	Kill Devil Hills
Volunteer Families Program	Raleigh

Ohio

United Cerebral Palsy of Greater Cincinnati	Cincinnati
---	------------

Oklahoma

Oklahoma Chapter of the National Multiple Sclerosis Society	Oklahoma City
Oklahoma Respite Resource Network	Statewide

Oregon

The Arc of Jackson County	Medford
Life Span Respite	Medford
Lifespan Respite Network of Jackson County	Medford
Malheur County Lifespan Respite	Ontario

Pennsylvania

CareBreak at the Watson Institute	Sewickley
Centre County (PA) Down Syndrome Society	State College
Cumberland Perry Respite	Carlisle
Cumberland County Aging & Community Services	Carlisle
Helping Hands-Healing Hearts	Pittsburgh
Mentors for Self Determination	Conneaut Lake
Intergenerational Center, Temple University	Philadelphia
PA Waiting List Campaign	Slatington
Partnership for Community Supports	Philadelphia
Pennsylvania Lifespan Respite Coalition	Statewide
Perry Link	Camp Hill
The Alliance for Community Respite Care	Pittsburgh
The Arc, Susquehanna Valley	Sunbury
The Watson Institute-Day and Overnight Respite Program	Sewickley
United Cerebral Palsy/Community Living and Support Services	Pittsburgh
UCP Central PA	Camp Hill
UCP of South Central Pennsylvania	Hanover
Vision for Equality, Inc.	Philadelphia

Rhode Island

Autism Project of Rhode Island	East Greenwich
Parent Support Network of Rhode Island	Johnston
Rhode Island Coalition of School Social Workers	Warwick
RI Parent Information Network, Inc.	Cranston
United Cerebral Palsy of Rhode Island,	Pawtucket

South Carolina

Alzheimer's Association SC Chapter	Anderson
Family Connection of South Carolina	Columbia
South Carolina Respite Coalition	Statewide

Tennessee

Tennessee Respite Coalition	Statewide
United Cerebral Palsy (UCP) of the Mid-South	Memphis

Texas

Adult Day Care Association of Texas	Houston
Center on Disability and Development, Texas A&M University	
Easter Seals North Texas	Dallas/Forth Worth
National Multiple Sclerosis Society – TX	

Private Providers Association of Texas	Austin
Rehabilitation, Education and Advocacy for Citizens with Handicaps, Inc	Fort Worth
Texas Assoc for Home Care & Hospice	Austin
Texas Respite Coalition	
The Arc of Greater Houston	
United Cerebral Palsy of Greater Houston, Inc	Houston
United Cerebral Palsy of Texas	Austin
Vermont	
Vermont Family Network	Williston
Vermont Family Voices	Statewide
Virginia	
Partnership for People with Disabilities	Richmond
Wisconsin	
Advocating for the Rights of Citizens (ARC) of the North	Washburn
ARC of the Northwoods	Ashland
Arts For All	Bayfield
Children's Service Society of Wisconsin	Milwaukee
Respite Care Association of Wisconsin	Madison
Bayfield County Department of Human Services	Washburn
Easter Seals SE WI	Milwaukee
Easter Seals WI	Madison
Epilepsy Foundation	Madison
Family Connections of SW WI	Lancaster
Family Respite Care Services Inc.	Janesville
Homes for Independent Living	Green Bay
Interfaith Older Adult Programs, Inc.	Milwaukee
Lifespan Respite Care Northern Network	Hurley
Lincoln County Respite Committee	Merrill
New Horizons North	Ashland
North Country Independent Living	Superior
Oconomowoc Residential Programs	Oconomowoc
Prader-Willi Homes of Oconomowoc	Oconomowoc
Respite Care Association of Wisconsin	Statewide
United Cerebral Palsy Of South Eastern Wisconsin	Milwaukee
United Cerebral Palsy-W Central Wisconsin	Eau Claire
Wisconsin Alliance for Infant Mental Health	Statewide
Wisconsin Board for People with Developmental Disabilities	Statewide
Wisconsin Family Assistance Center for Education Training and Support, Inc.	Statewide
Wisconsin Family Ties	Madison

