June 20, 2018

The Honorable Roy Blunt
Chairman
Appropriations Subcommittee on Labor, Health and Human Services, and Education
260 Russell Senate Office Building
Washington, DC  20510

The Honorable Patty Murray
Ranking Member
Appropriations Subcommittee on Labor, Health and Human Services, and Education
154 Russell Senate Office Building
Washington, DC  20510

The Honorable Tom Cole
Chairman
Appropriations Subcommittee on Labor, Health and Human Services, and Education
2358-B Rayburn House Office Bldg.
Washington, DC  20515

The Honorable Rosa DeLauro
Ranking Member
Appropriations Subcommittee on Labor, Health and Human Services, and Education
1016 Longworth House Office Bldg.
Washington, DC  20515

Dear Chairman Blunt, Ranking Member Murray, Chairman Cole and Ranking Member DeLauro:

We, the undersigned state and local coalitions, organizations and agencies representing all ages and disabilities, are writing to urge funding in the Fiscal Year 2019 Labor/HHS/Education Appropriations bill for respite and family caregiver support that provide a safety net for family caregivers across the lifespan. We are especially aware of the fiscal constraints facing Congress and the nation, and urge you to recognize the cost-benefits of investing in these proven prevention strategies. We are very appreciative of the increase provided in FY 2018 for the Lifespan Respite Care Program. To continue to reach more family caregivers who receive inadequate or no support, we are requesting a modest increase to $5 million in FY 2019. We also are very appreciative of the $30 million restoration provided in FY 2018 for the National Family Caregiver Support Program. At a minimum, we request that you protect the FY 2018 increase. However, if we are to begin to address the increasing need, we need to build upon the current level with a 12 percent increase ($21.7 m) in FY 2019.

Forty-three million family caregivers provide the vast majority of our nation’s long-term services and supports, permitting individuals of all ages to remain in their communities and avoid or delay more costly nursing home or foster care placements. AARP has estimated that family caregivers provide $470 billion in uncompensated care annually to adults, a staggering amount that is close to current federal and state spending on Medicaid health services and long-term services and supports combined ($553 billion).

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers. Yet, 85 percent of the nation’s family caregivers of adults do not receive respite. Of the nearly half of family caregivers of adults (44%) identified in the National Study of Caregiving who were providing substantial help with health care, fewer than 17% used respite. The percentage is similar for parents of children with special needs. For family caregivers caring for someone with Alzheimer’s, adults with developmental disabilities, individuals with Multiple Sclerosis (MS), ALS, spinal cord or traumatic brain injury, rare diseases, and grandparents raising grandchildren, respite is especially elusive. Families caring for children, teens and adults with autism, physical disabilities or mental health conditions also can’t
find or afford respite. A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, found that limited respite services do not address the needs of military caregivers.

Respite can save dollars by helping to avoid or delay out-of-home placements or hospitalizations. In a survey of family caregivers of individuals with MS, two-thirds said that respite care would help them keep their loved ones at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75 percent. Researchers at the University of Pennsylvania studied the Medicaid records of over 28,000 children with autism ages 5 to 21. They concluded that for every $1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization.

Lifespan Respite systems, which maximize existing resources, require that respite become more accessible and available to all family caregivers. As importantly, Lifespan Respite systems build respite capacity and improve quality by requiring states to focus on addressing respite provider/volunteer training and recruitment, start-up of new respite services, and affordability issues for family caregivers who are not eligible for any publicly funded respite services.

We are grateful for the increase for the Lifespan Respite Program in FY 2018 to $4.1 million. However, additional funding is needed to meet the escalating need. By investing in Lifespan Respite and other family and caregiver supports, the goal of avoiding or delaying more costly and unwanted institutional care, foster care, hospitalizations and emergency room use, can be reached. Such efforts that can help reduce Medicaid expenditures for long-term services and supports without limiting eligibility, quality, or services should be one of Congress’s top priorities.

The National Family Caregiver Support Program (NFCSP) was the first federal program to recognize the needs of the nation’s family caregivers who provide the backbone of long-term services and supports. NFCSP not only funds respite, but counseling, support groups, and caregiver training for family caregivers, primarily for those who are caring for the aging and for individuals of any age with Alzheimer’s or other dementias. It also provides limited supports for grandparents and older relatives to provide care for children under age 18 and to older parents and relative caregivers of adults with disabilities. However, funding for NFCSP has not kept up with the need.

We strongly urge you to fund Lifespan Respite at the modest request of $5 million and to ensure an increase in funding for the National Family Caregiver Support Program. If you would like more information, please contact Jill Kagan at the National Respite Coalition at jkagan@archrespite.org. Thank you for your attention to our request and for your support and recognition of the nation’s family caregivers.

Sincerely,

Alabama
Alabama Lifespan Respite Resource Network
Aaron's Staff Respite Care
Positive Maturity, Inc.
Arizona
Arizona Caregiver Coalition
The Arc of Arizona

Arkansas
Parent Advisory Council INC.

California
California Respite Association
Channel Islands Social Service
In Home Care Solutions
United Cerebral Palsy of the Inland Empire

Colorado
Colorado Respite Coalition
Easterseals Colorado

Florida
Florida Lifespan Respite Alliance
Renaissamae's Treasures Respite Service
The Unicorn Children's Foundation, Inc.

Georgia
Easterseals of Southern Georgia, Inc.
Georgia Community Support & Solutions

Hawaii
Hawaii Family Caregiver Coalition

Illinois
Illinois Respite Coalition
REST - Respite Education and Support Tools

Iowa
The Arc of Iowa

Kansas
Kansas Lifespan Respite Coalition

Louisiana
Evangeline Council on Aging

Maryland
Maryland Respite Care Coalition

Massachusetts
Advocates, Inc.
Mississippi
Alzheimer's Mississippi Community Links, Inc.
Families as Allies
Merit Health
Mississippi Coalition for Citizens with Disabilities
Mississippi Family Caregiver Coalition
National Alliance on Mental Illness - Mississippi
National Association of Social Workers, Mississippi Chapter
New Beginnings Adult Day Care, LLC

Missouri
Missouri Association of Area Agencies on Aging
St. Louis Arc
St. Louis Family Support and Respite Coalition

Montana
Montana Lifespan Respite Coalition

Nebraska
Nebraska Caregiver Coalition
Nebraska Respite Network Western Service Area Advisory Committee

Nevada
Age- and Dementia-Friendly Winnemucca and Humboldt County Project
Circle of Life Community Hospice
Cleveland Clinic Lou Ruvo Center for Brain Health
Friends of Parkinson’s, Inc
Nevada Lifespan Respite Care Coalition
Nevada Senior Services
Seniors in Service

New York
Lifespan of Greater Rochester
New York State Caregiving and Respite Coalition
Wellness Home Care, Ltd.

North Carolina
Area Agency on Aging Region A
Area Agency on Aging at Land of Sky Regional Council
Friendship Adult Day Services, Inc.
Lumber River Council of Governments
Southeastern Wake Adult Day Center

Oklahoma
OK Caregiver Coalition
Sooner SUCCESS
**Pennsylvania**
Alliance for Community Respite Care
The Arc of Greater Pittsburgh
Pennsylvania Respite Coalition

**Rhode Island**
Family Caregiver Alliance of Rhode Island

**South Carolina**
No Place Like Home of SC
South Carolina Respite Coalition

**Tennessee**
A Divine Miracle Adult Day Center
ALPS Adult Day Services
American Senior Care Centers, Inc.
Caregiver’s Respite
Empower Tennessee
Epilepsy Foundation Middle and West Tennessee
Family Support Program/Community Development Center
Tennessee Association of Adult Day Services
Tennessee Disability Coalition
Tennessee Federation for the Aging
Tennessee Justice Center
Tennessee Respite Coalition
The Arc Tennessee

**Texas**
Autism Lifeline Links Texas
College Nannies and Sitters of Katy/Bellaire

**Virginia**
Virginia Caregiver Coalition

**Washington**
Lifespan Respite Washington

**Wisconsin**
The Arc Wisconsin
WisconSibs, Inc
Respite Care Association of Wisconsin

**Saipan, MP**
Commonwealth Respite Service Program