

June 09, 2017

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 national organizations representing all ages and disabilities, are writing to urge funding in the Fiscal Year 2018 Labor/HHS/Education Appropriations bill for respite and other critical family support programs 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 requesting **\$5.0 million for the Lifespan Respite Care Program**. We are also requesting that, at a minimum, you fund **Title III E, the National Family Caregiver Support Program at \$158 million**, reflecting the level approved in the recent Older Americans Act reauthorization.

Forty-three million family caregivers provide a 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 statistic that exceeds 2013 federal and state spending on Medicaid health services and long-term services and supports combined.

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. 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, and grandparents raising grandchildren, respite is especially elusive. Families caring for children and teens with autism, physical disabilities or serious emotional disturbance 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 existing federal or state programs that support respite.

While we are grateful for the retention of the modest increase for the Lifespan Respite Program in FY 2017, the program is significantly underfunded at only \$3.36 million. However, by investing even this small amount in Lifespan Respite and other family and caregiver supports, the goal of avoiding or delaying more costly institutional care, hospitalizations and emergency room use, can be reached. 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.

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 relative caregivers of adults with disabilities. With recent enactment of the Older Americans Act, modifications to the NFCSP extend respite and caregiver support to older parents of adults with disabilities as well.

We strongly urge you to fund Lifespan Respite at the modest request of \$5 million and to ensure funding for the National Family Caregiver Support Program (\$158 million). 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,

ACCSES
Alliance for Retired Americans
Alzheimer's Association
Alzheimer's Foundation of America
Alzheimer's Impact Movement
American Association on Health and Disability
American Dance Therapy Association
American Foundation for the Blind

American Music Therapy Association
The Arc of the United States
Association of University Centers on Disabilities
Autism Society of America
Brain Injury Association of America
Caregiver Action Network
Christopher and Dana Reeve Foundation
The Elizabeth Dole Foundation
Family Caregiver Alliance, National Center on Caregiving
Family Voices
Generations United
The Jewish Federations of North America
Lakeshore Foundation
Lupus Foundation of America
Lutheran Services in America
The Michael J. Fox Foundation
National Alliance for Caregiving
National Association for Home Care and Hospice
National Association of Area Agencies on Aging (n4a)
National Alliance of Children's Trust & Prevention Funds
National Association of Social Workers (NASW)
National Association of State Directors of Developmental Disabilities Services
National Association of State Directors of Special Education (NASDSE)
National Association of State Head Injury Administrators
National Committee to Preserve Social Security and Medicare
National Council on Aging
National Military Family Association
National MPS Society
National Multiple Sclerosis Society
National Respite Coalition
Parent to Parent USA
Paralyzed Veterans of America
Rosalynn Carter Institute for Caregiving
Sibling Leadership Network
TASH
United Cerebral Palsy
Well Spouse Association