

April 29, 2019

The Honorable Rosa DeLauro
Chairwoman
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
Washington, DC 20515

The Honorable Tom Cole
Ranking Member
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
Washington, DC 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge funding in the Fiscal Year 2020 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 FYs 2018 and 2019 for the **Lifespan Respite Care Program**. To address the growing need to support family caregivers who are the linchpin of the nation's long-term services and supports system, we are requesting \$20 million in FY 2020 for this program and \$202.7 million for the **National Family Caregiver Support Program**.

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 rivals 2018 federal and state spending on Medicaid health services and long-term services and supports combined (\$582 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 struggle financially, but 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. 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. Despite recent positive outcomes for family caregivers reported in the NFCSP Outcome Evaluation from the Administration for Community Living, including the positive impact of respite and caregiver education on reducing caregiver burden, funding for NFCSP is not keeping up with the need.

We strongly urge you to fund Lifespan Respite at the modest request of \$20 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,

Alzheimer's Association
Alzheimer's Impact Movement
American Association of Caregiving Youth
American Association on Health and Disability
American Dance Therapy Association
Association of Assistive Technology Act Programs (ATAP)
Brain Injury Association of America
Caregiver Action Network
Caring Across Generations
Christopher & Dana Reeve Foundation
Family Caregiver Alliance, National Center on Caregiving
Family Voices

Generations United
Justice in Aging
Lakeshore Foundation
Lupus Foundation of America
National Association of Area Agencies on Aging (n4a)
National Association of Councils on Developmental Disabilities
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 Down Syndrome Congress
National Military Family Association
National Multiple Sclerosis Society
National Respite Coalition
Paralyzed Veterans of America
Rosalynn Carter Institute for Caregiving
TASH
Well Spouse Association