

June 21, 2021

The Honorable Patrick Leahy, Chairman
Senate Committee on Appropriations
Room S-128, The Capitol
Washington, D.C. 20510

The Honorable Rosa DeLauro, Chairwoman
House Committee on Appropriations
H-307, The Capitol
Washington, DC 20515

The Honorable Richard Shelby, Vice Chairman
Senate Committee on Appropriations
Room S-128, The Capitol
Washington, D.C. 20510

The Honorable Kay Granger, Ranking
Member
House Committee on Appropriations
H-307, The Capitol
Washington, DC 20515

Dear Sens. Leahy and Shelby and Reps. DeLauro and Granger:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge **\$14.2 million** in the Fiscal Year 2022 Labor/HHS/Education Appropriations bill for the **Lifespan Respite Care Program**, administered by the Administration on Aging, Administration for Community Living. This amount reflects the President's budget recommendation to double funding for this program in FY 2022. For more than a decade, and especially during the pandemic, respite provided by the program has been a vital safety net for the nation's family caregivers of both children and adults.

During the pandemic, social isolation and severe mental health issues among family caregivers intensified. The CDC found that "unpaid adult caregivers reported having experienced disproportionately worse mental health outcomes, increased substance use, and elevated suicidal ideation." The Lifespan Respite network responded with flexible respite options. For countless caregivers, respite became their only lifeline to supports, services, and vital human connection.

We are very appreciative of the increase provided in FY 2021 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 **\$14.2 million in FY 2022, the amount requested by the President**. This program received no emergency supplemental funding during the pandemic, yet Lifespan Respite grantees continued to respond to daily requests for respite and created innovative and flexible new ways to meet caregiver needs.

Fifty-three million family caregivers, up from 43.5 million just six years ago, 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 of adults provide \$470 billion in uncompensated care annually. Researchers at Boston Children's Hospital found that families caring for the most seriously ill children provide nearly \$36 billion worth of care annually. Their associated foregone earnings were over \$17 billion.

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers. Yet, 86 percent of the nation's family caregivers of adults do not receive respite. The percentage is similar for parents of children with special needs. For family caregivers caring for someone with Alzheimer's disease, adults with developmental disabilities,

individuals with Multiple Sclerosis (MS), ALS, traumatic brain injury, or rare diseases, as well as grandparents raising grandchildren and military and Veteran caregivers, 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.

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 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 the Lifespan Respite Program received in FY 2020 to \$7.1 million. However, the pandemic shined a harsh new light on family caregivers' escalating unmet needs. By investing in Lifespan Respite and other family caregiver supports, the goals of strengthening the wellbeing of the nation's family caregivers, and of avoiding or delaying costly out-of-home placements and unnecessary hospitalizations, can be reached.

We strongly urge you to fund Lifespan Respite at the modest request of \$14.2 million in the FY 2022 Labor, HHS and Education appropriations bill. This will potentially allow all states to receive funding. 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
ADvancing States
Aging Life Care Association®
Allies for Independence
ALS Association
Alzheimer's Association
Alzheimer's Foundation of America
Alzheimer's Impact Movement
American Academy of Pediatrics
American Association of Caregiving Youth
American Association on Health and Disability
American Association on Intellectual and Developmental Disabilities (AAIDD)
American Music Therapy Association
American Network of Community Options & Resources (ANCOR)
Association of Assistive Technology Act Programs (ATAP)
Association of University Centers on Disabilities (AUCD)
Autism Society of America
Brain Injury Association of America
Caregiver Action Network
Children's Trust Fund Alliance
CommunicationFIRST
Division for Early Childhood of the Council for Exceptional Children
Easterseals

Elizabeth Dole Foundation
Epilepsy Foundation
Family Caregiver Alliance, National Center on Caregiving
Family Voices
IDEA Infant and Toddler Coordinators Association
The Jewish Federations of North America
Lakeshore Foundation
Lupus Foundation of America
The Michael J. Fox Foundation for Parkinson's Research
National Adult Day Services Association
National Alliance for Caregiving
National Association of Area Agencies on Aging (n4a)
National Association of Councils on Developmental Disabilities
National Association of State Head Injury Administrators
National Council on Aging
National Down Syndrome Society
National Military Family Association
National Multiple Sclerosis Society
National Respite Coalition
Network of Jewish Human Service Agencies
Paralyzed Veterans of America
Pulmonary Hypertension Association
Rosalynn Carter Institute for Caregivers
Sibling Leadership Network
TASH
The Arc of the United States
United Cerebral Palsy
United Spinal Association
Well Spouse Association

cc: Senate Appropriations Subcommittee on Labor-HHS-Education
House Appropriations Subcommittee on Labor-HHS-Education