

June 11, 2025

Honorable Susan Collins, Chair
Senate Committee on Appropriations
Room S-128, U.S. Capitol
Washington, D.C. 20510

The Honorable Patty Murray, Vice Chair
Senate Committee on Appropriations
Room S-128, U.S. Capitol
Washington, D.C. 20510

The Honorable Tom Cole, Chairman
House Committee on Appropriations
H-307, U.S. Capitol
Washington, DC 20515

The Honorable Rosa DeLauro, Ranking
Member
House Committee on Appropriations
H-307, U.S. Capitol
Washington, DC 20515

Re: FY2026 Appropriations for the Lifespan Respite Care Program and the National Family Caregiver Support Program (OAA Title III-E) and Native American Caregiver Support Program (OAA Title VI-C)

Dear Chair Collins and Vice Chair Murray, Chairman Cole and Ranking Member DeLauro:

To address the growing need to support family caregivers who are the linchpin of the nation's long-term services and supports system, we, the undersigned national, state and local organizations representing all ages and disabilities, respectfully request that the House and Senate Subcommittees on Labor, Health and Human Services, Education, and Related Agencies and House and Senate Appropriations Committees provide \$20 million in funding for the Lifespan Respite Care Program, a funding level consistent with the bipartisan Member request led by Rep. Fitzpatrick and Rep. Dingell in a recent letter to the House Appropriations Committee. We are also requesting significant investments beyond current funding for the Older Americans Act Title III-E, National Family Caregiver Support Program (NFSCP) and Older Americans Act Title VI-C, Native American Caregiver Support Services. These programs are administered by the Administration for Community Living in the U.S. Department of Health and Human Services. Respite and caregiver supports provided by these programs ensure a vital safety net for the nation's family caregivers of both children and adults.

These are challenging times for children and adults with disabilities, older adults, and their family caregivers. The critical shortage of qualified direct care professionals to provide home and community-based services and supports is threatening the ability of individuals with disabilities and older adults to live at home and in the community. Moreover, the ability of the more than 60% of employed family caregivers to balance work and family responsibilities has become untenable.

At the same time, the Administration for Community Living's 2022 release of the National Strategy to Support Family Caregivers offers concrete actionable steps to support family caregivers, and ensure that people with disabilities and older adults can continue to live at home and in the community with support from family members. We have a unique opportunity in the FY 2026 appropriations bill to build on the increased awareness and momentum generated by the National Strategy, and implement the National Strategy's sound and reasonable recommendations for enhancing caregiver supports.

Family caregivers provide the vast majority of our nation's long term services and supports at an estimated \$600 billion annually, permitting individuals to remain in their communities and avoid or delay more costly out-of-home placements.

Respite care has been shown to help alleviate the stress that may occur because of unsupported and ongoing caregiving responsibilities. In addition, 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.

Family caregivers are not using respite care because of financial and access barriers. Lifespan Respite grants are unique in that they help states build respite capacity and improve quality by requiring states to focus on addressing respite provider training and recruitment and start-up of new respite services. The program also helps family caregivers who struggle financially to pay for respite, but are not eligible for any publicly-funded respite services.

The Older Americans Act Title III-E, National Family Caregiver Support Program (NFSCSP) funds respite, counseling, support groups, and caregiver training for family caregivers, including older parents and relative caregivers of adults with disabilities. Despite documented positive outcomes for family caregivers reported in the NFSCSP Outcome Evaluation from the Administration for Community Living, including the positive impact of respite and caregiver education on reducing caregiver burden, funding for NFSCSP has not kept up with the increasing need in the growing older population.

In conclusion, these funding increases are necessary to meet the needs of people with chronic illness and disabilities, older adults, and their families who have been under fiscal constraints over the past decade and continue to face considerable challenges due to the escalating direct care workforce crisis. 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 hospitalizations, can be reached.

Thank you for your consideration of this request and for your support and recognition of the nation's family caregivers. If you would like more information, please contact Jill Kagan with the National Respite Coalition at jkagan@archrespice.org.

Sincerely,

National

Access Ready Inc
ACCSES
ADvancing States
Alliance for Aging Research
American Academy of Pediatrics
American Association of Caregiving Youth
American Association on Health and Disability
American Music Therapy Association
American Network of Community Options and Resources (ANCOR)
American Occupational Therapy Association
American Therapeutic Recreation Association
Autism Society of America
Autistic Self Advocacy Network
Autistic Women & Nonbinary Network
Christopher & Dana Reeve Foundation
CommunicationFIRST
Disability Belongs
Elizabeth Dole Foundation
Epilepsy Foundation of America
Family Caregiver Alliance, National Center for Caregiving
Family Voices National
Generations United
Lakeshore Foundation
Lupus Foundation of America
National Adult Day Services Association
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Association of Social Workers (NASW)
National Center for Pediatric Palliative Care Homes
National Disability Rights Network (NDRN)
National Council on Aging
National Down Syndrome Congress
National Military Family Association
National Respite Coalition

Pulmonary Hypertension Association
The Arc of the United States
The Self-Direction Center
The Sibling Leadership Network
United Cerebral Palsy
United Spinal Association
USAging
Well Spouse Association

Alabama

Alabama Lifespan Respite
Joy Bells Alzheimer's and Dementia Ministries
United Cerebral Palsy of Huntsville

California

Channel Islands Social Services
Inland Respite, Inc.
KARE Crisis Nursery, Inc.
ONEgeneration
Tri-County Respite Care Service
United Cerebral Palsy of the Inland Empire

Colorado

Colorado Respite Coalition
Special Kids Special Families
The Arc - Jefferson, Clear Creek & Gilpin Counties

Delaware

Modern Maturity Center, Inc.

Idaho

Idaho Family Caregiver Alliance
John & Junes Mission

Illinois

CJE SeniorLife

Illinois Respite Coalition, Inc.

Indiana

Agape Respite Care, Inc.

Massachusetts

AgeSpan, Inc.

Federation for Children with Special Needs

Martha's Vineyard Center for Living

Massachusetts Lifespan Respite Coalition

Mystic Valley Elder Services

Riverside Community Care

South Shore Support Services

Mississippi

The Abigayle Adult Day Center

Missouri

Sandwiched KC

Montana

Montana Lifespan Respite Coalition

Nebraska

Nebraska Caregiver Coalition

Nevada

Nevada Lifespan Respite Care Coalition

New Mexico

New Mexico Caregivers Coalition

New York

Association on Aging in New York
Cayuga County Office for the Aging
Cortland County Office for Aging
Hamilton-Madison House
Heights and Hills
JASA - Brooklyn Caregiver Support Program
Lifespan Caregiver Wellness Respite Center
Lifespan of Greater Rochester, Inc.
New York State Caregiving and Respite Coalition
Schenectady County Senior and Long Term Care
Sundance Adult Day Program
University of Rochester Noyes Health Caregiver Support Program
Wayne County Department of Aging & Youth

North Carolina

Families and Communities Rising
The Center for Volunteer Caregiving

Ohio

Pause for Parents, Play for Kids, Inc.

Oklahoma

OKCares

Oregon

The Arc of Lane County
System of Care Advisory Council

South Carolina

Family Connection of SC
Leeza's Care Connection
South Carolina Respite Coalition

Tennessee

American Senior Care Centers, Inc.

Tennessee Association of Adult Day Services

Tennessee Caregiver Coalition

Washington

PAVE Lifespan Respite WA

Wisconsin

Barrier Buster Designs

Greater Wisconsin Agency on Aging Resources, Inc.

Respite Care Association of Wisconsin

The Respite Center (RISE Wisconsin)

Wisconsin Aging Advocacy Network

Wisconsin Family & Caregiver Support Alliance

cc:

The Honorable Shelly Moore Capito, Chair

Subcommittee on Labor, HHS, Education, and Related Agencies

Senate Appropriations Committee

The Honorable Tammy Baldwin, Ranking Member

Subcommittee on Labor, HHS, Education, and Related Agencies

Senate Appropriations Committee

The Honorable Robert Aderholt, Chairman

Subcommittee on Labor, HHS, Education, and Related Agencies

House Appropriations Committee

The Honorable Rosa DeLauro, Ranking Member

Subcommittee on Labor, HHS, Education, and Related Agencies

House Appropriations Committee