

February 24, 2020

The Honorable Mitch McConnell  
Majority Leader  
United States Senate  
Washington, DC 20510

The Honorable Chuck Schumer  
Minority Leader  
United States Senate  
Washington, DC 20510

The Honorable Lamar Alexander, Chairman  
Committee on Health, Education, Labor  
and Pensions  
U.S. Senate  
Washington, DC 20510

The Honorable Patty Murray, Ranking Member  
Committee on Health, Education, Labor and  
and Pensions  
U.S. Senate  
Washington, DC 20510

The Honorable Susan Collins  
U.S. Senate  
413 Dirksen Senate Office Building  
Washington, D.C. 20510

The Honorable Tammy Baldwin  
U.S. Senate  
709 Hart Senate Office Building  
Washington, D.C. 20510

Re: Lifespan Respite Care Program Reauthorization Act (S. 995)

Dear Leader McConnell, Leader Schumer, Chairman Alexander, Ranking Member Murray, Senator Collins, and Senator Baldwin:

We, the undersigned national, state and local organizations representing all ages and disabilities, are writing to offer our support for the bipartisan **Lifespan Respite Care Reauthorization Act (S. 995)** to reauthorize the Lifespan Respite Care Program at \$50 million over five years. We are very grateful that with your strong support, the bill was unanimously approved by the Senate Health, Education, Labor and Pensions Committee last October, and we now urge the Senate to take swift action to pass the bill. We also want to acknowledge and express our deep gratitude to Rep. James Langevin for his championing of Lifespan Respite in the House since 2003, when he first introduced the Lifespan Respite Care Act in Congress. He continued to lead the effort with subsequent reauthorization bills in every Congress since 2011.

Every day, millions of American families are faced with unexpected illness, disease, or disability. A soldier is injured in war, a spouse develops multiple sclerosis or Alzheimer's disease, or a child is diagnosed with a developmental or physical disability or chronic illness. These are but a few examples of events that can forever change an individual's and family's trajectory.

While each situation is unique, the one thing that they often have in common is the incredible role family caregivers play. Forty-three million family caregivers provide a vast majority of our nation's long-term care, permitting individuals of all ages to remain in their communities and avoid or delay nursing home or foster care placements.

While the benefits of family caregiving are plentiful, caregiving can take its toll. Respite—short-term care that offers individuals or family members temporary relief from the daily routine and stress of providing care—is a critical component to bolstering family stability and maintaining family caregiver health and well-being. Respite is a frequently requested support service among family caregivers, but 85% of family caregivers of adults receive no respite and the percentage is similar for parents caring for their children with special needs.

The Lifespan Respite Care Program, through competitive grants to states to establish or enhance statewide Lifespan Respite systems, work to maximize existing resources and help ensure that quality respite is available and accessible to all family caregivers. With more than half of care recipients under age 75 and more than one-third under age 50, Lifespan Respite rightly recognizes caregiving as a lifespan issue and serves families regardless of age or disability.

Though the program has been drastically underfunded since its inception, thirty-seven states and the District of Columbia have received grants and are engaged in impressive work such as identifying and coordinating respite services available through various state agencies, including veterans caregiver services; helping unserved families pay for respite through participant-directed voucher programs; addressing the workforce shortage by recruiting and training respite workers and volunteers; and building capacity by awarding mini-grants to community and faith-based agencies for new services; and raising awareness about respite through public education campaigns. Enactment of the Lifespan Respite Care Reauthorization Act is necessary to continue this excellent momentum, better coordinate and supply respite care to our nation's 43 million family caregivers through statewide Lifespan Respite programs and ensure that states are able to sustain the great work they have begun and still allow new states to receive a grant.

We thank you for your commitment to individuals living with disabilities, older individuals in need of assistance and support, and the loved ones who care for them and we look forward to continuing to work with you as the bill moves forward. If you would like more information, please contact Jill Kagan with the National Respite Coalition at [jkagan@archrespite.org](mailto:jkagan@archrespite.org).

Sincerely,

***National Organizations***

AARP  
ACCSES  
Aging Life Care Association  
Alliance for Aging Research  
Alliance for Retired Americans  
ALS Association  
Altarum  
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  
American Music Therapy Association  
American Network of Community Options and Resources ([ANCOR](#))  
American Occupational Therapy Association  
American Therapeutic Recreation Association  
Autism Society of America  
Caregiver Action Network  
Caregiver Voices United  
Caregivers on the Homefront  
CommunicationFIRST

Easterseals  
Elizabeth Dole Foundation  
Epilepsy Foundation  
Family Caregiver Alliance, National Center on Caregiving  
Family Voices  
Generations United  
Lakeshore Foundation  
Leading Age  
Lupus Foundation of America  
National Alliance for Caregiving  
National Asian Pacific Center on Aging (NAPCA)  
National Association for Home Care and Hospice  
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 Head Injury Administrators  
National Committee to Preserve Social Security and Medicare  
National Down Syndrome Congress  
National Foster Parent Association  
National Multiple Sclerosis Society  
National Respite Coalition  
Network of Jewish Human Service Agencies  
Paralyzed Veterans of America  
Rosalynn Carter Institute for Caregiving  
Sibling Leadership Network  
The Arc of the United States  
United Cerebral Palsy National  
Well Spouse Association  
Women's Institute for a Secure Retirement (WISER)

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### ***State and Local Organizations***

#### ***Alabama***

Alabama Governor's Office on Disability  
Alabama Home Health Services  
Alabama Lifespan Respite Resource Network  
Alabama Lifespan Respite Coalition  
Madison County 310 Board  
North Alabama Community Care  
United Cerebral Palsy of Alabama  
United Cerebral Palsy of Huntsville and Tennessee Valley, Inc.  
United Cerebral Palsy of Mobile and Central Alabama  
West Alabama Area Agency on Aging

#### ***Arizona***

Arizona Caregiver Coalition  
Benevilla  
Posada Life Adult Day Services

SunTree Adult Day Health & School For Seniors

**California**

Association of Caregiver Resource Centers  
YMCA Childcare Resource Service

**Florida**

Florida Lifespan Respite Alliance

**Idaho**

Center for the Study of Aging  
Families Together  
John & Junes Mission, Inc.  
Idaho Caregiver Alliance  
Kids 1st Disability Resource Center  
Legacy Corps for Veteran and Military Families/Jannus  
Rays for Rare  
Relatives As Parents INC.  
Senior Connection

**Illinois**

Illinois Respite Coalition

**Kansas**

Kansas Lifespan Respite Coalition

**Maryland**

Maryland Respite Care Coalition

**Mississippi**

Mississippi Family Caregiver Coalition

**Montana**

Developmental Educational Assistance program (DEAP)  
Montana Lifespan Respite Coalition

**Nebraska**

Nebraska Caregiver Coalition  
Nebraska Lifespan Respite Network

**Nevada**

Nevada Lifespan Respite Care Coalition

**New Jersey**

The Family Resource Network  
Caregivers of New Jersey

***New York***

Fulton Co Office for Aging & Youth  
Livable Communities Caregiver Collaborative  
Livable Communities Alzheimer's/Dementia Collaborative  
Livable Communities Intergenerational Collaborative  
New York State Caregiving and Respite Coalition

***Oklahoma***

Oklahoma Caregiver Coalition  
Sooner Success

***Pennsylvania***

Alliance for Community Respite Care

***South Carolina***

Central Midlands Area Agency on Aging  
Charleston Area Senior Citizens, Inc  
Down Syndrome Association of the Upstate  
Evolve Senior Solutions  
Family Connection of South Carolina  
Federation of Families of South Carolina  
Leeza's Care Connection  
Richland/Lexington Disability and Special Needs Board  
South Carolina Autism Society  
South Carolina Respite Coalition  
South Carolina Spinal Cord Injury Association  
Tri-County Adult Day Services, Inc

***Tennessee***

Tennessee Respite Coalition

***Washington***

Washington PAVE  
Washington State Respite Coalition

***Wisconsin***

Greater WI Agency on Aging Resources, Inc.  
Inclusa  
Respite Care Association of Wisconsin