

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@archrespice.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)

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