

October 30, 2019

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  
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 Chairman Alexander, Ranking Member Murray, Senator Collins, and Senator Baldwin:

We, the undersigned national organizations representing all ages and disabilities, are writing to offer our support for the **Lifespan Respite Care Reauthorization Act (S. 995)** manager's amendment to reauthorize the Lifespan Respite Care Program at \$50 million over five years. We also want to thank you for your leadership in supporting the nation's family caregivers as you consider this bill in full Committee. 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, though 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,

ACCSES

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

Autism Society of America

Caregiver Action Network

Caregiver Voices United

CommunicationFIRST

Easterseals

Epilepsy Foundation

Family Voices

Generations United

Lakeshore Foundation

Lupus Foundation of America

National Alliance for Caregiving

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

Paralyzed Veterans of America

Sibling Leadership Network  
The Arc of the United States  
United Cerebral Palsy National  
Well Spouse Association