

September 20, 2024

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

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

Re: Lifespan Respite Care Program Reauthorization Act (S. 4325)

Dear Senator Collins and Senator Baldwin:

The undersigned national organizations are writing in strong support of the **Lifespan Respite Care Reauthorization Act (S. 4325)** to reauthorize the Lifespan Respite Care Program at \$50 million over five years, and to urge swift passage. We also want to thank you for your leadership in supporting the nation's family caregivers as you champion this legislation.

On September 17, 2024, the House passed HR 6160, its version of the Lifespan Respite Care Reauthorization Act under suspension of the rules. While we are grateful for an extension of the program for another five years, we remain in steadfast support of S. 4235, because it is the only version of the bill that amends the definition of family caregivers to ensure that young caregivers will be eligible for respite support under this program.

More than 5 million children under the age of 18 are providing significant caregiving to their parents or siblings with disabilities or chronic conditions or to their aging grandparents. The Elizabeth Dole Foundation has also helped to shed light on the significant numbers of young children who provide caregiving assistance in military families. This change in the law will finally allow them to receive the respite break they deserve and need, allow them to remain in school, and to become healthy and productive adults.

In 2022, the Administration for Community Living released the National Strategy to Support Family Caregivers to provide the first-ever national framework to better serve the nation's family caregivers regardless of where they live or the age or condition of the person in their care. It was created to help Federal agencies, States and local communities, and the private sector, identify actions, programs and policies that will address the direct care workforce crisis and serve the millions of family caregivers who currently have no supports or services but are expected to provide the vast majority of long-term services and supports.

Every day, millions of American families are faced with unexpected illness. A soldier is injured in war, a spouse develops multiple sclerosis or Alzheimer's disease, or a child is diagnosed with a developmental, intellectual or physical disability, Autism, 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. Fifty-three million family caregivers provide a 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 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 86% of family caregivers of adults receive no respite and the percentage is similar for parents caring for their children with special needs.

The RAISE Family Caregiving Advisory Council and the Supporting Grandparents Raising Grandchildren Council, with input from thousands of family caregivers and professionals, who were responsible for development of the Strategy, thought respite was important enough to mention it 42 times in the Strategy and to recommend that family caregivers be able to obtain respite services that meet their unique needs.

The Lifespan Respite Care Program can help states and communities meet the promise of the National Strategy, though competitive grants to states to establish or enhance statewide coordinate Lifespan Respite systems, work to maximize existing resources, and help ensure that quality respite is available, affordable, 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-eight 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 self-directed voucher programs; addressing the workforce shortage by recruiting and training respite workers and volunteers; and building capacity by awarding mini-grants to community, volunteer, 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 family caregivers through statewide Lifespan Respite programs and ensure that states are able to sustain the great work they have begun.

We thank you for your commitment to children and adults living with disabilities and chronic conditions, older adults 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.

Sincerely,

AARP
ACCSES
Access Ready Inc.
ADvancing States
Aging Life Care Association®

Allies for Independence
American Academy of Pediatrics
American Association of Caregiving Youth
American Association on Health and Disability
American Association of People with Disabilities (AAPD)
American Music Therapy Association
Autism Society of America
Autistic Self Advocacy Network
Autistic Women and Nonbinary Network
Christopher & Dana Reeve Foundation
Disability Belongs
Elizabeth Dole Foundation
Epilepsy Foundation
Family Caregiver Alliance
Lakeshore Foundation
National Alliance for Caregiving
National Association of Councils on Developmental Disabilities
National Association of State Directors of Developmental Disabilities Services
National Disability Rights Network (NDRN)
National Down Syndrome Congress
National Down Syndrome Society
National Federation of Families
National Military Family Association
National Respite Coalition
Rosalynn Carter Institute for Caregivers
Sibling Leadership Network
TASH
The Arc of the United States
USAging
Well Spouse Association