

April 1, 2019

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

The Honorable Jim Langevin
U.S. House of Representatives
2077 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Cathy McMorris Rodgers
U.S. House of Representatives
1035 Longworth House Office Building
Washington, D.C. 20515

Dear Senator Collins, Senator Baldwin, Representative Langevin and Representative McMorris Rodgers:

We, the undersigned national organizations representing all ages and disabilities, are writing to offer our fervent support for and endorsement of the **Lifespan Respite Care Reauthorization Act** to reauthorize the Lifespan Respite Care Program at \$200 million over five years. We also want to thank you for your leadership in supporting the nation's family caregivers.

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 value of family caregivers. 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. AARP has estimated that in 2013, family caregivers provided \$470 billion in uncompensated care to adults, a staggering statistic that exceeds federal and state spending on Medicaid health services and long-term services and supports that same year.

While the benefits of family caregiving are plentiful, caregiving can take its toll—with older spousal family caregivers experiencing higher mortality rates, rates of acute and chronic conditions, and depression than noncaregivers. 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. Not surprisingly, high burden family caregivers (defined as those who assist their loved one

with personal care such as getting dressed or bathing) cite lack of respite as one of their top three concerns.

To help provide family caregivers the support they need, the Lifespan Respite Care Program was enacted in 2006 with strong bipartisan support. The program provides competitive grants to states to establish or enhance statewide Lifespan Respite systems that 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 or mini-grants to community and faith-based agencies; building respite capacity by recruiting and training respite workers and volunteers; and raising awareness about respite through public education campaigns. Originally authorized through Fiscal Year 2011, 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 [REDACTED]

Sincerely,

AARP

Alzheimer's Association

Alzheimer's Foundation of America

Alzheimer's Impact Movement

American Association of Caregiving Youth

American Association on Intellectual and Developmental Disabilities (AAIDD)

American Dance Therapy Association

American Music Therapy Association

The Arc

Association of University Centers on Disabilities (AUCD)

Autism Society of America

Brain Injury Association of America

Caregiver Action Network

Caring Across Generations
Christopher & Dana Reeve Foundation
Easterseals
Elizabeth Dole Foundation
Epilepsy Foundation
Family Caregiver Alliance, National Center on Caregiving
Family Voices
Generations United
The Jewish Federations of North America
Justice in Aging
LeadingAge
Lupus Foundation of America
The Michael J. Fox Foundation for Parkinson's Research
National Alliance for Caregiving
National Alliance of Children's Trusts and Prevention Funds
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 Social Workers (NASW)
National Association of State Directors of Developmental Disabilities Services
National Association of State Head Injury Administrators
National Association of States United for Aging and Disabilities
National Down Syndrome Congress
National Down Syndrome Society
National Hospice and Palliative Care Organization
National Military Family Association
National Multiple Sclerosis Society
National Respite Coalition
Paralyzed Veterans of America
Program to Improve Eldercare, Altarum
Rosalynn Carter Institute for Caregiving
Sibling Leadership Network
TASH
United Spinal Association
Well Spouse Association