

August 15, 2014

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

Dear Representative Langevin:

We, the undersigned national organizations representing all ages and disabilities, are writing to offer our fervent support for the **Lifespan Respite Care Reauthorization Act (H.R.4683)**, a free-standing bill that reauthorizes the Lifespan Respite Care Program at \$15 million a year for five years, and for the **Military and Veteran Caregiver Services Improvement Act of 2014 (H.R. 4892)** that includes a five year reauthorization of the Lifespan Respite Care Program at \$15 million annually and makes more explicit the eligibility of veterans and their 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. Sixty-five million family caregivers provide 80% of our nation's long-term care, permitting individuals to remain in their communities and avoid or delay nursing home or foster care placements. AARP has estimated that family caregivers provide nearly \$450 billion in uncompensated care annually, a staggering statistic that exceeds annual federal and state spending on Medicaid health services and long-term services and supports.

While the benefits of family caregiving are plentiful, caregiving can take its toll—with 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 nearly 90% of family caregivers receive no respite. 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.

The concerns for military caregivers were recently brought to the forefront in the compelling report *Hidden Heroes: America's Military Caregivers* from the RAND

Corporation with support from the Elizabeth Dole Foundation. According to RAND, caregiver duties for post-9/11 veterans alone can be estimated as worth close to \$3 billion (in 2011 dollars); the costs of lost productivity among post-9/11 caregivers are \$5.9 billion (in 2011 dollars). According to the RAND report, significant gaps exist in the array of programs, policies, and initiatives designed to support military caregivers, including respite services. The **Military and Veteran Caregiver Services Improvement Act of 2014 (H.R. 4892)** reflects many of the report's findings and recommendations to improve and expand the VA caregiver program, including the recommendation to make respite care more widely available to military caregivers, and to consider alternative respite strategies for this population – the very goals the Lifespan Respite Program has the flexibility to help accomplish.

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 almost one-third (28%) 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-one states 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-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 and better coordinate and supply respite care to our nation's 65 million family caregivers through statewide Lifespan Respite programs.

We thank you for your commitment to individuals living with disabilities and the loved ones who care for them and we look forward to continuing to work with you as these bills move forward. If you would like more information, please contact Jill Kagan at [jbkagan@archrespite.org](mailto:jbkagan@archrespite.org).

Sincerely,

ACCSES

American Association on Intellectual and Developmental Disabilities  
American Association for Geriatric Psychiatry  
American Association on Health and Disability  
American Music Therapy Association

American Psychological Association  
Association of Assistive Technology Act Programs (ATAP)  
Association of University Centers on Disabilities  
Autism National Committee  
Caregiver Action Network  
Christopher & Dana Reeve Foundation  
Easter Seals  
Epilepsy Foundation  
Family Caregiver Advocacy  
Lupus Foundation of America  
Lutheran Services in America Disability Network  
National Alliance for Caregiving  
National Alliance of Children's Trust & Prevention Funds  
National Association of Area Agencies on Aging (n4a)  
National Association of State Directors of Developmental Disabilities Services  
National Association of State Directors of Special Education  
National Association of State Head Injury Administrators  
National Association of States United for Aging and Disabilities  
National Center on Caregiving, Family Caregiver Alliance  
National Child Abuse Coalition  
National Council on Aging  
National Council on Independent Living  
National Disability Rights Network  
National MS Society  
National Respite Coalition  
National Senior Citizens Law Center  
OWL-The Voice of Women 40+  
Paralyzed Veterans of America  
Parkinson's Action Network  
Rosalynn Carter Institute for Caregiving  
The ALS Association  
The Arc  
United Spinal Association  
Well Spouse Association