

December 14, 2011

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

The Honorable Cathy McMorris Rodgers
U.S. House of Representatives
2421 Rayburn House Office Building
Washington, D.C. 20515

Dear Representatives Langevin and McMorris Rodgers:

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. 3266).

Every day, 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 an intellectual or developmental disability. These instances can forever change an individual's and family's trajectory, but through the maze, the incredible value of family caregivers is undeniable. Sixty five million family caregivers provide 80% of our nation's long-term care, permitting loved ones to remain in their communities and avoid or delay premature admission to institutional facilities. In 2009, AARP 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 high mortality rates, rates of acute and chronic conditions, and depression. 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 good health of the family caregiver. Respite is the most 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.

To help address this significant void and 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 states have received grants and are engaged in impressive work such as identifying and coordinating respite services available through various state agencies, building respite capacity by recruiting and training respite workers, and raising awareness about respite through public education campaigns. Originally authorized through Fiscal Year 2011, swift 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 H.R. 3266 moves forward.

Sincerely,

Alzheimer's Foundation of America
American Association for Geriatric Psychiatry
American Association of People with Disabilities
American Association on Intellectual and Developmental Disabilities
American Dance Therapy Association
American Network of Community Options and Resources
American Occupational Therapy Association
American Psychological Association
Association of Assistive Technology Act Programs
Association of University Centers on Disabilities
Autism National Committee
Bazelon Center for Mental Health Law
Brain Injury Association of America
Christopher & Dana Reeve Foundation
CWLA
Easter Seals
Epilepsy Foundation
Family Caregiver Alliance
Family Voices
Generations United
LeadingAge
Mental Health America
National Alliance for Caregiving
National Family Caregivers Association
National Association of Area Agencies on Aging (n4a)
National Association of States United for Aging and Disabilities
National Association of State Head Injury Administrators
National Association of Social Workers
National Association of State Directors of Special Education

National Child Abuse Coalition
National Council on Aging
National Down Syndrome Society
National Federation of Families for Children's Mental Health
National MPS Society
National Multiple Sclerosis Society
National Respite Coalition
OWL-The Voice of Midlife and Older Women
Paralyzed Veterans of America
Rosalynn Carter Institute for Caregiving
Sibling Leadership Network
TASH
The ALS Association
The Arc
United Cerebral Palsy
United Spinal Association
Well Spouse Association