



Legislative Alert
January 2016

**Seeking Congressional Cosponsors for
*Lifespan Respite Care Reauthorization Act of 2015 (HR 3913)***

The ***Lifespan Respite Care Reauthorization Act of 2015*** (HR 3913), is a bipartisan reauthorization of the Lifespan Respite Care Program, authorizing it through FY 2020 at \$15 million annually. The bill was introduced by Rep. Jim Langevin (D-RI) and Rep. Gregg Harper (R-MS) and it has been referred to the House Energy and Commerce Committee.

The Lifespan Respite Care Program (LRCP): The U.S. Administration for Community Living (ACL) provides competitive grants to state agencies in concert with Aging and Disability Resource Centers and state respite coalitions to make quality respite available and accessible to family caregivers regardless of age or disability through establishment of State Lifespan Respite Systems.

Funding: LRCP has been level funded at \$2.3 - \$2.5 million each year since FY 2009. The program received an increase of \$1 million in FY 2016. The new legislation authorizes \$75 million over five years (FY16-FY 20).

Implementation Status: Thirty-three states and DC have received LRCP grants from the US Administration for Community Living (ACL) since 2009 (see www.archrespite.org).

→ ACTION:

- Ask your Representative to cosponsor the *Lifespan Respite Care Reauthorization Act of 2015* (HR 3913). Call your Representatives at 202-225-3121 and ask for health or disability staff. If you don't reach them, leave a message!
- For additional contact information or to send an email to your Member of Congress, visit <http://www.house.gov/representatives/>.

Respite Among Most Critically Necessary and Beneficial Family Support Services

- The nation's 43 million family caregivers provide the vast majority of long-term services and supports to individuals of all ages living at home, yet 85% of those caring for adults have not received respite services (*National Alliance for Caregiving (NAC) and AARP Public Policy Institute, Caregiving in the US, 2015*).
- Family caregivers have higher rates of acute and chronic conditions and depression than noncaregivers. Respite, often the most frequently requested service by family caregivers, has been shown to help maintain caregiver health, bolster family stability, keep marriages intact, and help avoid or delay more costly out-of-home placements.

- Caregiving is a lifespan issue. Care for the aging population is a growing issue, but currently more than half of adult care recipients (53%) are between the ages of 18 and 75 (*NAC and AARP, 2015*). According to the most recent National Survey of Children with Special Health Care Needs, more than 11 million children under age 18 have special health care needs¹ (*Health Resources and Services Administration, 2013*).
- The estimated value of family caregiving of adults is \$470 billion annually. This amount is more than total Medicaid spending in 2013, and as much as the total sales of the world's largest company, Wal-Mart (*AARP Public Policy Institute, Valuing the Invaluable, 2015*).
- University of Pennsylvania researchers studied the records of over 28,000 children with autism ages 5 to 21 who were enrolled in Medicaid in 2004. They concluded that for every \$1,000 states spent on respite services in the previous 60 days, there was an 8 percent drop in the odds of hospitalization (*Mandell, David S., et al, 2012*).
- In an Institute of Medicine (IOM) report on living with chronic illness, authors concluded that “although respite services provide proven benefits, most caregivers feel that what’s out there is not enough” and “more services should be offered” (*IOM, 2012*).

Lifespan Respite State Accomplishments

- Many lifespan respite programs, including those in **Alabama, Arizona, Delaware, Montana, Nebraska, Nevada, North Carolina, Oklahoma, Rhode Island, South Carolina, Tennessee, Virginia, and Washington**, have successfully used consumer-directed respite vouchers for serving underserved populations, such as individuals with Multiple Sclerosis or ALS, adults with intellectual or developmental disabilities (I/DD), or those on waiting lists for services.
- States, including **Idaho, Illinois, Iowa, and Nebraska**, are now able to offer support for emergency respite services.
- **Alabama, Arkansas, Massachusetts, Nebraska, Ohio, Pennsylvania, South Carolina and Tennessee** and many more are providing new volunteer or faith-based respite services.
- Innovative and sustainable respite services have been funded in **Colorado, Massachusetts, North Carolina and Ohio** through mini-grants to community-based agencies and have demonstrated benefits to family caregivers and their loved ones.
- The recruitment and training of new respite providers are priorities in many Lifespan Respite states, including **New Hampshire, Virginia, and Wisconsin**.
- **Alabama, Arizona, Colorado, Delaware, Massachusetts, Nebraska, New Hampshire, Virginia, and Texas** have developed statewide registries to help family caregivers find respite.

¹The U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) as “...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”