URGE CONGRESS TO FUND LIFESPAN RESPITE AT $10 MILLION IN FY 2020

The Lifespan Respite Care Program (LRCP): The U.S. Administration for Community Living (ACL) provides competitive grants to state agencies working with Aging and Disability Resource Center/No Wrong Door Systems and state respite coalitions. The program’s purpose is to make quality respite more available to family caregivers regardless of age or disability through coordinated State Lifespan Respite Systems, providing planned and emergency respite services through voucher programs, recruiting and training respite providers and volunteers, and supporting community and faith based agencies to provide respite.

Funding: Funding for the LRCP was $4.1 million in both FY 2018 and FY 2019. The House-passed FY 2020 spending bill includes $10 million for Lifespan Respite and the Senate Appropriations Committee recommends $6.1 million.

Program Status: Thirty-seven states and DC have received LRCP grants from the U.S. Administration for Community Living (ACL) since 2009 (see www.archrespite.org).

FY 20 FUNDING REQUEST: The National Respite Coalition and its national partners are requesting $10 million in FY 2020 for Lifespan Respite.

ACTION: Call your Senators and Representatives at 202-224-3121. When connected, ask for appropriations or health staff. If you don’t reach them, leave a message! Visit this easy tool for contact information.

MESSAGE: Please support an increase in the Lifespan Respite Care Program and fund it at $10 million in FY 2020. Increased funding will allow states to serve more family caregivers and bring the program to more states. Use the talking points in this alert and make it personal!

Lifespan Respite Grants Make a Difference

- Grantees are delivering services and helping families pay for respite, especially for those caring for someone between the ages of 18-60, including adults with physical disabilities, MS, ALS, brain injury or paralysis, or I/DD; children, adults, and the aging on Medicaid waiver
Grantees are building respite capacity through provider training and recruitment. Others have issued small grants to community-based organizations to start new respite programs or initiate unique volunteer and faith-based initiatives to provide respite.

The LRCP allows grantees to coordinate respite services to reach family caregivers more efficiently, provide person and family-centered services, and make respite more available to underserved families.

State Lifespan Respite Accomplishments

- In describing the Lifespan Respite Care Program, a distinguished panel from the National Academies of Sciences, Engineering, and Medicine concluded in the report *Families Caring for an Aging America*, “Although the program is relatively small, respite is one of the most important caregiver supports.”

- AL, CO, DE, IL, MD, MT, NE, NV, NC, OK, RI, SC, TN, VA, WA, and WI Lifespan Respite current and former grantees are successfully using consumer-directed respite vouchers to help family caregivers pay for respite for underserved populations, such as individuals with Multiple Sclerosis or ALS, adults with intellectual or developmental disabilities (I/DD), or those on waiting lists for Medicaid home and community-based services.

- Caregivers in NE’s Lifespan Respite Network reported significant decreases in stress levels, fewer physical and emotional health issues, reductions in anger and anxiety, and reported being in a better financial situation when receiving respite. AL Lifespan Respite’s voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite.

- Innovative and sustainable respite services funded in AL, CO, MA, NY, NC, and PA through mini-grants to community-based agencies are also demonstrating benefits to family caregivers and their loved ones.

- Lifespan Respite grantees in AL, AR, CO, NE, NY, PA, RI, SC, TN and others are providing new volunteer or faith-based respite services.

- States, including AL, IL, MD, ND and NE, offer support for emergency respite services.

- States, including AL, NY, NV, and others are collaborating with No Wrong Door systems to improve respite information and access.

- Respite provider recruitment and training to address the direct care worker shortage are priorities among most state grantees, including AL, CO, MA, NE, NV, NY, SC and WI.

Respite – A Critically Necessary and Beneficial Family Support Service

- 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
Family caregivers have higher rates of acute and chronic conditions and depression than noncaregivers. Respite, the most requested service by family caregivers, has been shown to help maintain caregiver health, bolster family stability, keep marriages intact, and help avoid or delay costlier out-of-home placements.

In a recent evaluation by the U.S. Administration for Community Living, caregivers who received 4 or more hours of respite care per week had a decrease in self-reported burden over time. As respite hours per week increased, so did the probability of a more favorable response regarding caregivers’ perception that services helped them continue caregiving (Administration for Community Living, December 2018).

Caregiving is a lifespan issue. Providing care for older adults is a growing concern, but currently more than half of adult care recipients (53%) are between the ages of 18 and 75 (NAC and AARP, 2015). More than 14 million children under age 18 have special health care needs (Health Resources and Services Administration, 2016).

Respite Reaps Cost Savings

- In these times of serious budget constraints, the economic value of respite is exceptional. Delaying nursing home care of just one individual with a chronic condition for several months can save Medicaid, private insurance, or the family tens of thousands of dollars.

- In 2013, the estimated value of family caregiving of adults was $470 billion -- more than total Medicaid spending that year, and as much as the total sales of the world’s largest company, Wal-Mart (AARP Public Policy Institute, Valuing the Invaluable, 2015).

- Researchers at the University of Pennsylvania 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).

- American businesses lose $17.1 to $33.6 billion annually in lost productivity costs related to employees’ caregiving responsibilities (MetLife Mature Market Institute, 2006).

See the NRC updated Fact Sheet Respite Benefits and Cost-Savings for more!