URGE CONGRESS TO FUND LIFESPAN RESPITE AT $10 MILLION IN FY 2021

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 that provide direct services, recruit and train respite providers and volunteers, and support community and faith-based agencies to provide respite.

Funding: Funding for the LRCP was $6.1 million in FY 2020.

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 21 FUNDING REQUEST: The National Respite Coalition and its national partners are requesting $10 million in FY 2021 for Lifespan Respite.

ACTION: Call your Senators and Representatives at 202-225-3121. 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 funding for the Lifespan Respite Care Program and fund it at $10 million in FY 2021. 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

- The LRCP provides direct planned and emergency respite services to family caregivers, ensures services are person and family-centered, and makes respite more available and affordable to underserved families through coordinated systems and partnerships.

- Grantees are delivering services and helping families pay for respite, including families caring for adults with Alzheimer’s disease, MS, ALS or I/DD; children, adults, and the aging on Medicaid waiver waiting lists; grandparents raising grandchildren; rural family caregivers; culturally diverse groups and others identified as having unmet needs in the state.
▪ Grantees are addressing the workforce shortage through provider training and recruitment. Others have issued small grants to community-based organizations to start new respite programs or initiate innovative volunteer and faith-based initiatives to provide respite.

▪ 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.

**Respite Reaps Cost Savings**

▪ The economic value of respite is exceptional. Delaying nursing home care for one individual with a chronic condition for several months can save Medicaid, private insurance, or the family tens of thousands of dollars.

▪ In 2017, the estimated value of family caregiving of adults was $470 billion -- more than all out-of-pocket spending on U.S. health care in 2017 ($366 billion) for that year. Families caring for children with special health care needs provide nearly $36 billion worth of care annually.

▪ 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 confirmed 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.

▪ American businesses lose $17.1 to $33.6 billion annually in lost productivity costs related to employees’ caregiving responsibilities and related stress.

**Respite – A Critically Necessary and Beneficial Family Support Service**

▪ More than 50 million family caregivers of children and adults 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, and a similar percentage caring for children, have not received respite services.

▪ 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 ages 18 and 75. According to the most recent National Survey of Children’s Health, more than 13 million children under age 18 have special health care needs.

▪ Respite, the most requested service by family caregivers, has been shown to reduce stress and social isolation, help improve caregiver health and wellbeing, 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.
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.

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

- 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.

To read more about current Lifespan Respite grantee activities and accomplishments, see **State Lifespan Respite Grant Objectives, Outcomes and Activities**.

For more Talking Points, including the number of family caregivers in your state and the value of their caregiving, visit National Respite Coalition at [https://archrespite.org/national-respite-coalition#TalkingPoints](https://archrespite.org/national-respite-coalition#TalkingPoints) or contact NRC at [jkagan@archrespite.org](mailto:jkagan@archrespite.org).