URGE SENATE TO FUND LIFESPAN RESPITE AT $10 MILLION IN FY 2021
RESPITE NEED IS MORE URGENT NOW DURING THE ONGOING PANDEMIC!

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. The LRCP did not receive any emergency supplemental funding for COVID-19.

Program Status: Thirty-seven states and DC have received LRCP grants from the U.S. Administration for Community Living (ACL) since 2009, but funding increases have been limited since then (see archrespite.org).

FY 21 FUNDING REQUEST: The National Respite Coalition and its national partners are requesting $10 million in FY 2021 for Lifespan Respite. The House-passed appropriations bill includes $10 million!

ACTION: Call your Senators at 202-224-3121 and urge them to support $10 million for Lifespan Respite in the Senate Labor-HHS-Education Appropriations bill. When connected, ask for appropriations or health staff. If you don’t reach them, leave a message! Visit this easy tool for additional contact information.

MESSAGE: An increase is desperately needed for the Lifespan Respite Care Program. During the pandemic, family caregivers have been more isolated and stressed. Respite may be their only support. Use talking points in this alert and make it personal!

Lifespan Respite Grants Make a Difference, Especially During the Pandemic

- During the pandemic, Lifespan Respite grantees and their partners have been a lifeline to family caregivers. They continue to provide respite services when possible, and use creative and meaningful approaches to support and continuously connect to family caregivers.
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, even during the pandemic.

Grantees are 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 that has intensified during COVID-19 through online provider training and recruitment. They are also providing greater flexibility in respite voucher program eligibility, for both caregivers and providers, to make it easier to participate.

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 86% of those caring for adults, and a similar percentage caring for children, have not received respite services.

Caregiving is a lifespan issue. Sufficient care for older adults is a growing concern, but more than half of adult care recipients (54%) are between ages 18-75. According to the most recent National Survey of Children’s Health, nearly 14 million children under 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 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 and COVID-19 Responses

Grantees and their partners rapidly adapted respite services and supports to meet isolated family caregiver needs during COVID-19 in innovative ways including regular check-in phone calls, connections to food and basic supports, live Facebook events, online activities to keep care recipients engaged, home-delivered or mailed care packages with activities for caregivers and care recipients, online support groups, stress reduction and self-care webinars, and other virtual respite strategies.

**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. As a result of the pandemic:

- **OK** increased the voucher amount; expanded provider eligibility to include someone who lives with the caregiver and care recipient; and lifted the household income requirement.
- **VA** instituted similar voucher flexibilities to meet increasing requests for respite.
- In **NV, CO** and other states, grantees have extended time limits for voucher use to maximize flexibility in meeting family caregiver needs.

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

Many grantee 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, *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.