



## **Bipartisan Lifespan Respite Care Reauthorization Act of 2024 (S. 4325)**

***Pass the Lifespan Respite Care Reauthorization Act (S. 4325) in the Lame Duck Session!***

The ***Lifespan Respite Care Reauthorization Act of 2024 (S. 4325)*** amends the Public Health Service Act to reauthorize the program through FY 2029 at \$50 million over five years, and amends the definition of family caregiver to include individuals under age 18. The bill was introduced in the Senate by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI). On June 18, 2024, it was reported favorably by the Senate Health, Education, Labor and Pensions (HELP) Committee and is awaiting floor action in the Senate during the lame duck session.

On September 17, 2024, the House passed HR 6160, its version of the Lifespan Respite Care Reauthorization Act, under suspension of the rules. The House bill sponsors are Rep. Marcus Molinaro (R-NY) and Rep. Tony Cárdenas (D-CA).

The **National Respite Coalition** and 36 other national organizations are grateful for an extension of the program for another five years, but **remain steadfast in their support of S. 4325**.<sup>1</sup> It is the only version of the bill that amends the definition of family caregivers to ensure that caregiving youth are eligible for respite care. More than 5 million children under the age of 18 are providing significant caregiving to their parents, including those in military families; to siblings with disabilities or chronic conditions; or to their aging grandparents. This significant policy change will finally provide access to the respite support they deserve and need, allowing them to remain in school and become healthy and productive adults.

***The Lifespan Respite Care Program (LRCP):*** The U.S. Administration for Community Living (ACL) awards competitive grants to states working with Aging and Disability Resource Center/No Wrong Door Systems and state respite coalitions. The program's purpose is to ensure that quality respite is available to family/friend caregivers, regardless of age or disability, through direct services, provider recruitment and training, and coordinated state Lifespan Respite systems.

***Funding:*** Funding for the LRCP was \$10 million in FY 2023 and FY 2024.

***Program Status:*** Thirty-eight states and DC have received at least one LRCP grant from ACL since 2009. Currently, 25 states have federal Lifespan Respite Grants.

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<sup>1</sup> Letter from 37 national organizations to Senators Collins and Baldwin urging swift passage of S 4325.

<https://archrespite.org/wp-content/uploads/2024/09/Organization-letter-in-support-of-S.-4325-Lifespan-Respite.pdf>

## Respite Reaps Cost Savings

- In 2021, the estimated value of family caregiving of adults was **\$600 billion -- more than all out-of-pocket spending on U.S. health care (\$433 billion)**. Families caring for children with special health care needs provide **nearly \$36 billion worth of care annually**.
- The economic value of respite is exceptional. Delaying nursing home care for one individual with a chronic condition or Alzheimer's disease for several months can save Medicaid, private insurance, or the family tens of thousands of dollars.
- American businesses lose \$17.1 to \$33.6 billion annually in lost productivity costs related to employees' caregiving responsibilities and related stress.

## Lifespan Respite Grants Make a Difference

- The LRCP provides 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. See *Key Accomplishments of Lifespan Respite Grantees*.
- Grantees **deliver care and help underserved or unserved families pay for respite**, including adults with Alzheimer's disease, MS, ALS, or I/DD; those on Medicaid waiver waiting lists; grandparents raising grandchildren; rural family caregivers; and culturally diverse groups.
- Grantees are addressing the **workforce crisis** through provider training and recruitment, and by funding innovative **volunteer and faith-based respite** programs.
- Caregivers in **NE's Lifespan Respite Network** reported significant decreases in stress, physical and emotional health issues, anger and anxiety, and reported a better financial situation when receiving respite. **AL Lifespan Respite's** voucher program found substantial decreases in the number of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite.

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

- More than 53 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.
- 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 an evaluation by the U.S. Administration for Community Living, caregivers who received 4 or more hours of respite care/week had a decrease in self-reported burden. As respite hours increased, so did the probability of a more favorable response regarding caregivers' perception that services helped them continue caregiving.