



Lifespan Respite Care Act (P.L. 109-442)
FY 11 Appropriations Request



The Lifespan Respite Care Act authorizes competitive grants to state agencies working in concert with Aging and Disability Resource Centers and non-profit state respite coalitions or organizations to make quality respite available and accessible to family caregivers regardless of age or disability through the establishment of State Lifespan Respite Systems.

Appropriations Status: The Lifespan Respite Care Act, signed into law in 2006, received first-time funding (\$2.5 million) in FY 09 and level funding in FY 2010. The President recommended \$5 million for FY 2011 as a component of his Middle Class Initiative. However, the law authorizes Congress to spend \$94.8 million in FY 2011. Thirty-eight (38) House Members signed a letter to the House Labor/HHS/Education Appropriations Subcommittee requesting full funding for Lifespan Respite in FY 11. Eight Senators sent a similar letter to Senate Appropriations Subcommittee chairs.

Implementation Status: Twelve states received Lifespan Respite grants from the US Administration on Aging (AoA) in FY09 to jump start development of statewide respite systems. AoA will award additional state grants in the summer of 2010 (see www.archrespite.org).

→ FY11 Labor, HHS, Education Appropriations Request: The ARCH National Respite Coalition and the over 200 national, state and local member organizations of the Lifespan Respite Task Force are requesting \$94.8 million, the amount authorized by law for fiscal year (FY) 2011, for the Lifespan Respite Program.



Respite Among Most Critically Necessary and Beneficial Family Support Services

Respite Need is Great, Supply Limited.

- Family caregivers have higher mortality rates, rates of acute and chronic conditions, and depression. Respite, the most frequently requested support service, has been shown to provide family caregivers with relief necessary to maintain their own health, bolster family stability, keep marriages intact, and avoid or delay more costly nursing home or foster care placements. Yet, respite is in short supply or inaccessible for all age and disability groups.
- The nation's 65 million family caregivers provide 80% of long-term care. Caring for the aging population is a growing problem, but currently more than half of care recipients (56%) are under age 75, and almost one-third (28%) are under age 50. Caregiving is a lifespan issue. These

family caregivers provide an estimated \$375 billion in uncompensated care, an amount almost as high as Medicare spending (\$432 billion in 2007) and more than total spending for Medicaid, including federal and state contributions and medical and long-term care (\$311 billion in 2005).

Respite can be a tool in economic recovery.

- In these times of serious budget constraints, the economic value of respite is exceptional. Delaying nursing home or institutional 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.
- American businesses lose \$17.1 to \$33.6 billion annually in lost productivity costs related to caregiving responsibilities. Respite can help alleviate some of the stress working caregivers face. A recent study from the National Alliance on Caregiving and Evercare demonstrated that the economic downturn has had a particularly harsh effect on family caregivers. The study found that six in ten caregivers are workers and during this current economic downturn, 50% of them are less comfortable with taking time off from work to care for a family member or friend. A similar percentage (51%) says the economic downturn has increased the amount of stress they feel about being able to care for their relative or friend.
- In an Iowa survey of parents of children with disabilities, a significant relationship was demonstrated between the severity of a child's disability and their parents missing more work hours than other employees. They also found that the lack of available respite care appeared to interfere with parents accepting job opportunities.
- Lifespan Respite programs can also be an economic stimulus by creating more jobs, since they are required to conduct respite provider recruitment and training.

Lifespan Respite is Demonstrated Success

- The Lifespan Respite Care Program is based on model systems in Alabama, Oregon, Nebraska, Tennessee, Wisconsin and Oklahoma, which provide easy access to affordable, quality respite; ensure flexibility to meet diverse needs; and assist with locating, training, and paying respite providers.
- State Lifespan Respite programs have been cited as exemplary by the National Conference of State Legislators and highlighted by the National Governor's Association and the White House Conference on Aging.
- No other federal program mandates respite as its sole focus; helps ensure respite quality or choice; or allows funds for respite start-up, training and coordination regardless of age or disability.

Summary of Lifespan Respite Care Act (PL 109-442)

Use of Funds: The bill would authorize funds requiring state grantees to:

- ★ develop or enhance lifespan respite programs at the state and local levels;
- ★ provide planned and emergency respite for family caregivers of children and adults;
- ★ train and recruit respite workers and volunteers;
- ★ provide information to caregivers about available respite and support services; and
- ★ assist caregivers in gaining access to such services.

Grantees would have the option of using funds for training programs for family caregivers in making informed decisions about respite services; for other services essential to the provision of respite; and for training and education for new caregivers.

What is a Lifespan Respite Program?

Lifespan respite programs provide coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs.

Who Can Access Lifespan Respite Programs?

Caregivers who are family members, foster parents, or other adults providing unpaid (clarified n report language) care for an adult or child with a special need may access these programs. Adult with special need is defined broadly as a person 18 years of age or older who requires care or supervision to meet the person's basic needs, to prevent physical self-injury or injury to others, or to avoid placement in an institutional facility. A child with a special need is a person less than 18 years of age who requires care or supervision beyond that required of children generally to meet the child's basic needs or prevent physical self-injury or injury to others.

Lead Agency Eligibility

Funds would be provided on a competitive grant basis to states through Aging and Disability Resource Centers in collaboration with public or private nonprofit state respite coalitions or organizations (memorandum of agreement required in application). Priority is given to applicants who show the greatest likelihood of implementing or enhancing lifespan respite care statewide.

Application Submission

The Governor submits application on behalf of the State Agency that administers the Older American's Act, the State's Medicaid program, or another agency designated by the Governor.

Federal Administration

Secretary of Health and Human Services is required to work in cooperation with the National Family Caregiver Support Program Officer of the Administration on Aging and other respite care programs within the Department to ensure coordination of respite for family caregivers.

Funding Authorization: \$30 million for FY07, \$40 million for FY08, \$53.3 million for FY09, \$71.11 million for FY2010 and \$94.8 for FY2011.

National Resource Center: Establishes National Resource Center on Lifespan Respite Care.

GAO Report: Report on Lifespan Respite Programs required by 2011.

Prepared by the ARCH National Respite Coalition. For more information, please contact Jill Kagan at jbkagan@verizon.net, by phone at 703-256-9578 or visit www.archrespite.org. Updated March 2010.