Support Lifespan Respite Care Funding

Sending Office: Honorable James R. Langevin
Sent By: Katherine.Lee@mail.house.gov

Dear Colleague,

On behalf of more than 41 million family caregivers of adults and aging family members, as well as more than 13 million parents of children with special health care needs, we urge you to join us in sending the attached letter to House appropriators requesting $10 million for the Lifespan Respite Care program in fiscal year (FY) 2021.

Respite care provides temporary relief for family members engaged in the full-time task of caring for their loved ones who are aging or have disabilities. It also decreases the need for professional long-term care, resulting in savings to the health care system and taxpayers. Access to respite services has been shown to improve caregiver health and well-being; promote family stability; avoid or delay more costly out-of-home placements and reduce the likelihood of abuse and neglect. As the only federal program to address respite accessibility and affordability issues for families regardless of age or disability status, Lifespan Respite Care serves a critical and unique purpose.

According to a report issued by the AARP Public Policy Institute, the annual economic value of uncompensated family caregiving to the U.S. economy was estimated at $470 billion in 2017, more than all out-of-pocket spending on health care ($366 billion) for that year. With proper community supports like respite services, we can prevent the shift of these costs onto our health care system. Lifespan Respite Care has already provided grants to 37 states and the District of Columbia to help build respite care networks and provide respite to family caregivers across the country, but too many families still lack access to these services.

We hope you will join us in supporting our nation’s family caregivers by signing onto the attached
March 13, 2020

Dear Chairwoman DeLauro and Ranking Member Cole,

As you prepare the Fiscal Year 2021 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, we respectfully request that you include $10 million for Lifespan Respite Care Act (P.L. 109-442) programs.

Respite care provides temporary relief for family members engaged in the full-time task of caring for their family members who are aging or have disabilities. Whether tending to a mother with Alzheimer’s disease, a husband injured in Afghanistan, or a child with autism, the more than 50 million family caregivers in the U.S. provide approximately 80 percent of long-term services and supports. In fact, according to a report issued by the AARP Public Policy Institute, the annual economic value of uncompensated family caregiving to the U.S. economy was estimated at $470 billion in 2017, more than all out-of-pocket spending on US health care for that year.

Although the benefits of family caregiving are plentiful, it can take an emotional, mental and physical toll. Respite is the most frequently requested support service among family caregivers; however, the vast majority of family caregivers still go without respite care. Access to respite services has been shown to improve caregiver health and well-being; promote family stability; reduce the likelihood of
abuse and neglect; and avoid or delay the need for admission to costlier institutional settings, resulting in significant savings for the health care system and taxpayers.

The Lifespan Respite Care Program was created by Congress in 2006 as the only federal program to address respite issues for families regardless of age or disability. While some respite services are offered to certain populations through initiatives under the Department of Veterans Affairs and Medicaid, the lack of coordination and resources continues to impede access to these crucial supports. This program has already provided grants to 37 states and the District of Columbia to help coordinate federal, state and local resources; streamline the delivery of planned and emergency respite services; provide services for unserved groups; recruit and train respite workers; and train caregivers themselves. For families and individuals who don’t qualify for other public or private respite funding, these programs may be holding out the only helping hand. For wounded service members and veterans returning with traumatic brain injuries and other polytraumas, Lifespan Respite systems could be the lifeline their families must turn to in their new roles as life-long family caregivers. Further, Lifespan Respite is often the only open door for families affected by conditions and diseases with an earlier onset, like multiple sclerosis, since many existing respite programs have age restrictions and are targeted towards children or the aging.

With proper community supports like respite services, we can prevent the dramatic shift of these costs onto our health care system. The Lifespan Respite Care program is the only federal program that stands ready to meet these goals with funds for respite start-up, training, and coordination. We urge you to include $10 million for Lifespan Respite Care Act programs in the FY21 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, and we look forward to working with you on cost-effective and proven ways to support our nation’s family caregivers.

Related Legislative Issues

Selected legislative information: Appropriations, Civil Rights, Health Care, Veterans
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