Support Lifespan Respite Care Funding

Support Lifespan Respite Care Funding in the FY24 Labor-HHS Appropriations Bill

Deadline: COB March 22

FY23 cosigners: Dingell, Fitzpatrick, Barragan, Carson, Connolly, Delgado, DeSaulnier, Larson, Moulton, Norton, Panetta, Pingree, Yarmuth

Dear Colleague,

On behalf of more than 38 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 below letter to House appropriators requesting $20 million for the Lifespan Respite Care program in Fiscal Year (FY) 2024, which reflects prominent recommendations to increase respite care options that were included in the recently released National Strategy to Support Family Caregivers.

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, as well as recruitment and training of respite care workers to address the direct care workforce crisis, Lifespan Respite Care serves a critical and unique purpose, especially during the COVID-19 pandemic.

We hope you will join us in supporting our nation’s family caregivers by signing onto the below letter.

Sincerely,

Debbie Dingell               Brian Fitzpatrick
Member of Congress          Member of Congress
Dear Chairs Aderholt and Ranking Members DeLauro:

As you prepare the Fiscal Year (FY) 2024 Labor, Health and Human Services, Education, and Related Agencies Appropriations bill, we respectfully request that you include at least $20 million for Lifespan Respite Care Act 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. Family caregiving is always a balancing act, but over the past two years, caregivers have been juggling more than ever. From changing schedules to searching for personal protective equipment (PPE) and adjusting to telework, family caregivers have met the challenges of the pandemic head-on. Whether tending to a mother with Alzheimer’s disease, a husband injured in Afghanistan, or a child with autism, 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 $600 billion in 2021, more than all out-of-pocket spending on U.S. 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 and was reauthorized by the 116th Congress. 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 38 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 the only available 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 at least $20 million for Lifespan Respite Care Act programs in the FY24 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.

Thank you for your consideration of this important request.

Sincerely,