

April 23, 2015

The Honorable Tom Cole
Chairman
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
2358-B Rayburn House Office Bldg.
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Appropriations Subcommittee on Labor,
Health and Human Services, and Education
1016 Longworth House Office Bldg.
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

We, the undersigned national organizations representing all ages and disabilities, are writing to urge funding in the Fiscal Year 2016 Labor/HHS/Education Appropriations bill for respite and other critical family support programs that provide a safety net for family caregivers across the lifespan. We are especially aware of the fiscal constraints facing the nation, and urge you to recognize the cost-benefits of investing in these proven prevention strategies. We are requesting **\$5.0 million for the Lifespan Respite Care Program**, the amount included in the President's FY 2016 budget. We are also seeking support for the **National Family Caregiver Support Program (\$150 million)**, the **Native American Caregiver Support Program (\$6.8 million)**, and for the new **Family Support program (\$15 million)** proposed by the President.

In 2011, the first baby boomer turned 65. Each day, another 10,000 turn 65 and this trend will continue for the next 15 years. While the growth of the aging population raises critical family caregiving issues, it is critical to note that a majority (56%) of the individuals being cared for by the nation's family caregivers are under age 75 and 28% are under age 50. Family caregiving is not just an aging issue, but also a lifespan one.

A poll released by AARP in conjunction with the launch of the bipartisan, bicameral Assisting Caregivers Today (ACT) Caucus found that more than three quarters of registered voters 40 and over (77%) say that Congress should make it a priority to improve resources for family caregivers. When asked what services or resources would be most helpful for family caregivers, eight in ten current, former, and future caregivers say that having information about caregiver resources (88%) and respite care (85%) would be somewhat or very helpful.

Respite is out of reach for the vast majority of family caregivers caring for adults or children with disabilities or chronic conditions. Close to 90% of the nation's 65 million family caregivers do not receive respite. For family caregivers caring for someone with Alzheimer's, adults with developmental disabilities, individuals with Multiple Sclerosis (MS), ALS, spinal cord or traumatic brain injury, respite is especially elusive. Families caring for children and teens with autism, physical disabilities or serious emotional disturbance also can't find or afford respite. A 2011 survey of nearly 5,000 caregivers of individuals with intellectual and developmental disabilities conducted by The Arc found that more than 75% reported problems finding respite.

Respite can help save dollars by avoiding or delaying out-of-home placements or hospitalizations. In a survey of family caregivers of individuals with MS, two-thirds said that

respite care would help them keep their loved ones at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75%.

Research has documented the cost savings resulting from respite services. Researchers at the University of Pennsylvania studied the Medicaid records of over 28,000 children with autism ages 5 to 21. They concluded 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.

Lifespan Respite systems, which maximize existing resources, require that respite become more accessible and available to all family caregivers. As importantly, Lifespan Respite systems build respite capacity and improve quality by requiring states to focus on respite provider/volunteer training and recruitment, start-up of new respite services, and affordability issues for family caregivers who are not eligible for any existing federal or state programs that support respite.

The Lifespan Respite Care program is significantly underfunded at \$2.3 million. However, by investing even this small amount in Lifespan Respite and other family and caregiver supports, the goal of avoiding or delaying more costly institutional care, hospitalizations and emergency room use, can be reached. Any effort that can help reduce Medicaid expenditures for long-term services and supports and preserve the program's integrity, should be on the front burner.

The National Family Caregiver Support Program (NFCSP) was the first federal program to recognize the needs of the nation's family caregivers who provide the backbone of long-term services and supports. NFCSP not only funds respite, but counseling, support groups, and caregiver training for family caregivers, primarily for those who are caring for the aging and for individuals of any age with Alzheimer's or other dementias. It also provides limited supports for grandparents and other older relatives to provide care for adults and children with disabilities.

The new Family Support Program is proposed by the President under the authority of Title IV of the Older Americans Act of 1965, as amended, and Section 163 of the Developmental Disabilities Assistance and Bill of Rights Act. This initiative will utilize known, evidence-based approaches to develop and implement a sustainable national strategy to provide supports that bolster the ability of families to provide high-quality care for their loved ones. At the same time, it will allow families to maintain a quality of life for themselves by accessing multi-dimensional, flexible support and leveraging and enhancing their local community resources.

A poll released by AARP in conjunction with the launch of the bipartisan, bicameral Assisting Caregivers Today (ACT) Caucus We strongly urge you to fund Lifespan Respite at the modest request of \$5 million and to ensure funding for the National Family Caregiver Support Program (\$150 million), the Native American Caregiver Support Program (\$6 million), and ACL's Family Support Program (\$15 million). More than 65 million family caregivers in the US are counting on you this year. If you would like more information, please contact Jill Kagan at the National Respite Coalition at jkagan@archrespite.org. Thank you for your attention to our request and for your support and recognition of the nation's family caregivers.