Mr. Chairman, I am Jill Kagan, Chair, National Respite Coalition (NRC), a network of state respite coalitions, respite providers, family caregivers, and national, state and local organizations that support respite. We are requesting that the Subcommittee include $5.0 million for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services, in the FY 2019 Labor, HHS, and Education Appropriations bill. These modest increases will enable:

- State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient’s age or disability, to have access to affordable respite.
- Improvement in respite quality and expansion of respite capacity; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for both formal and informal respite services.

**Respite Care Saves Money and is it Helpful to the People it Serves**

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for individuals with Alzheimer’s or avoiding hospitalization for children with autism can save Medicaid billions of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every $1,000 states spent on respite, there was an 8% drop in the odds of hospitalization (Mandell, et al., 2012). Respite may reduce administrative burdens, help delay or avoid facility-based placements, improve maternal employment (Caldwell, 2007), strengthen marriages
(Harper, 2013), and significantly reduce caregiver stress levels linked to improved caregiver health (Zarit, et al., 2014). With at least two-thirds (66%) of family caregivers in the workforce (Mantos, 2015), U.S. businesses lose from $17.1 to $33.6 billion per year in lost productivity of family caregivers (MetLife Mature Market Institute, 2006). Higher absenteeism among working caregivers costs the U.S. economy an estimated $25.2 billion annually (Witters, 2011). Respite for working family caregivers could improve job performance, saving employers billions.

**Who Needs Respite?** More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015). The estimated economic value of family caregiving of adults alone is approximately $470 billion annually (AARP Public Policy Institute, 2015). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two out of three (66%) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers (Congressional Budget Office, 2013).

Immediate concerns about how to provide care for a growing aging population are paramount. However, caregiving is a lifespan issue with the majority (53%) of family caregivers caring for someone between the ages of 18 and 75 (NAC and AARP, 2015). In addition, the most recent National Survey of Children’s Health found that 14.6 million children under age 18 have special health care needs (National Survey of Children’s Health, 2016).

National, State and local surveys have shown respite to be the most frequently requested service by family caregivers (Maryland Caregivers Support Coordinating Council, 2015; The Arc, 2011; National Family Caregivers Association, 2011). Yet, 85% of family caregivers of adults are not receiving respite services at all (NAC and AARP, 2015). Nearly half of family caregivers of
adults (44%) identified in the *National Study of Caregiving* were providing substantial help with health care tasks. Despite their high level of care, fewer than 17% of this group used respite 
(*Wolff, 2016*). The Elizabeth Dole Foundation has recommended that respite should be more widely available to military caregivers (*Ramchand, et al., 2014*). The Dole Foundation’s Respite Impact Council found that traditional respite does not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

**Respite Barriers and the Effect on Family Caregivers.** While most families want to care for family members at home, research shows that family caregivers are at risk for emotional, mental, and physical health problems (*Family Caregiver Alliance, 2006; American Psychological Association, 2012; Spillman, J., et al., 2014*). When caregivers lack effective coping styles or are depressed, care recipients may be at risk for falling, developing preventable secondary health conditions or limitations in functional abilities. The risk of care recipient abuse increases when caregivers are depressed or in poor health (*American Psychological Association, nd*).

Respite, that has been shown to ease family caregiver stress, is too often out of reach or completely unavailable. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found that caregivers report physical fatigue (88%), emotional stress (81%) and upset or guilt (81%), yet more than 75% could not find respite (*The Arc, 2011*). Respite may not exist at all for those with Alzheimer’s, ALS, MS, spinal cord or traumatic brain injuries, or children with serious emotional conditions or autism. Barriers to accessing respite include fragmented services, cost, a critically short supply of well-trained respite providers, and lack of information about respite. Lifespan Respite is designed to help states eliminate these barriers through improved coordination and capacity building.
**Lifespan Respite Care Program Helps.** The federal Lifespan Respite program administered by ACL provides competitive grants to eligible state agencies. Congress appropriated $2.5 million each year from FY09-FY12 and slightly less in FY13-FY15 due to sequestration. In FY16 and FY17, the program received $3.3 million. Since 2009, 37 states and DC have received Lifespan Respite Grants. We are grateful for the increase in funding to $4.1 million in the FY18 Omnibus spending bill, which will allow ACL to fund several new states.

States are required to establish statewide coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide planned and emergency respite services, train and recruit respite workers and volunteers and assist caregivers in accessing respite. Lifespan Respite helps states maximize use of limited resources across age and disability groups and deliver services more efficiently to those most in need. Increasing funding, even slightly, could allow funding of several new states and help current grantees complete their ground-breaking work, serve the unserved, and help integrate services and grant activities into statewide long-term services and support systems.

**How is Lifespan Respite Program Making a Difference?** In describing the Lifespan Respite Care Program, a distinguished panel from the National Academies of Sciences, Engineering, and Medicine recently concluded in the report *Families Caring for an Aging America*, “Although the program is relatively small, respite is one of the most important caregiver supports.” With limited funds, Lifespan Respite grantees are engaged in innovative activities:

- **AL, AZ, DE, MT, NE, NV, NC, OK, RI, SC, TN, VA, and WA**, have successfully used consumer-directed respite vouchers for serving underserved populations, such as individuals with MS
or ALS, adults with intellectual or developmental disabilities (I/DD), rural caregivers, or those on waiting lists for services.

- **AL, ID, IL, IA, and NE** offer emergency respite support.
- **AL, AR, CO, NE, NY, OH, PA, SC and TN** implemented new volunteer or faith-based respite.
- Innovative and sustainable respite services, funded in **CO, MA, NC and OH** through mini-grants to community-based agencies, have documented benefits to family caregivers.
- Respite provider recruitment and training are priorities in **AR, NE, NH, SC, VA, and WI**.

Additional partnerships between state agencies are changing the landscape. The AZ Lifespan Respite program housed in Aging and Adult Services partnered with AZ’s Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the state’s Transit Administration to develop mobile respite to serve isolated rural areas of the state. States are building respite registries and “no wrong door systems” in partnership with Aging and Disability Resource Centers to help family caregivers access respite and funding sources. States are developing long-term sustainability plans, but without continued federal support, many of the grantees will be cut off before these initiatives achieve their full impact.

No other federal program has respite as its sole focus, helps ensure respite quality or choice, and supports respite start-up, training or coordination. We urge you to include $5 million in the FY 19 Labor, HHS, and Education appropriations bill. Families will be able to keep loved ones at home, saving Medicaid and other federal programs billions of dollars.
References


American Psychological Association (nd). Caregiver Briefcase: Family Caregiver Well-Being is Important to Care Recipient Health. 


