Mr. Chairman, I am Jill Kagan, Chair, National Respite Coalition (NRC), a network of state respite coalitions, providers, caregivers, and national, state and local organizations. We are requesting $20 million for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services, in the FY 2020 Labor, HHS, and Education Appropriations bill. The increase will enable: 1) State replication of Lifespan Respite best practices to allow family caregivers, regardless of the care recipient’s age or disability, to access affordable respite; 2) improved respite quality and expanded respite provider capacity; and 3) greater consumer direction by providing family caregivers with information on how to find, use and pay for respite services.

**Respite Care Saves Money and Benefits Families.** 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 and 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 help delay or avoid facility-based placements (Gresham, 2018; Avison, et al., 2018), improve maternal employment (Caldwell, 2007;), strengthen marriages (Harper, 2013), and significantly reduce caregiver depression, stress and burden levels linked to caregiver health (Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; 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). The University of NE Medical Center conducted a survey of caregivers receiving respite through the NE Lifespan Respite Program and found that 36% of family caregivers reported not having enough money at the end of the month to make ends meet, but families overall reported a better financial situation when receiving respite (Johnson, J., et al., 2018).

**Who Needs Respite?** More than 43 million adults in the U.S. are family caregivers of an adult or child with a disability or chronic condition (National Alliance for Caregiving (NAC). The estimated economic value of family caregiving of adults is approximately $470 billion annually (Reinhard, et al., 2015). Eighty percent of those needing long-term services and supports (LTSS) are living at home. Two-thirds of older people with disabilities receiving LTSS at home receive 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 2017 National Survey of Children’s Health found that 13.3 million children under age 18 have special health care needs (Child and Adolescent Health Measurement Initiative, 2019).

National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers (Anderson, L, et al., 2018; Maryland Caregivers Support Coordinating Council, 2015). 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*).

**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. In a survey of more than 3000 caregivers of individuals with intellectual and developmental disabilities (ID/DD), nine in ten reported that they were stressed. Nearly half (49%) reported that finding time to meet their personal needs was a major problem. Yet, more than half of the caregivers of individuals with ID (52%), Autism Spectrum Disorder (ASD) (56%) or ID and ASD (60%) reported that it was difficult or very difficult to find respite care (*Anderson, L., et al., 2018*). 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. 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. Since 2009, 37 states and DC have received Lifespan Respite grants. 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. We are grateful for the increase in funding to $4.1 million in the last two years. 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 care, train and recruit respite workers and volunteers and assist caregivers in accessing respite. Lifespan Respite helps states maximize use of limited resources and deliver services more efficiently to those most in need. Increasing funding could allow funding of several new states and help current grantees complete their ground-breaking work, serve the unserved, and 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 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.” 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 to serve underserved populations, such as individuals with Alzheimer’s disease, traumatic brain injury, MS or ALS, adults with intellectual or developmental disabilities (I/DD), rural caregivers, or those on waiting lists for services.
• **AL's** respite voucher program found a substantial decrease in the percentage of caregivers reporting how often they felt overwhelmed with daily routines after receiving respite. Caregivers in **NE's** Lifespan Respite program reported significant decreases in stress levels, fewer physical and emotional health issues, and reductions in anger and anxiety.

• **Innovative and sustainable respite services**, funded in **AL, CO, MA, NC, and NY** through mini-grants to community-based agencies, also have documented benefits to family caregivers.

• **AL, IA, MD** and **NE** offer emergency respite and **AL, AR, CO, NE, NY, PA, RI, SC, TN** implemented new volunteer or faith-based respite.

• **Respite provider recruitment and training** are priorities in **AR, NE, NY, SC, VA, and WI**.

  State agency partnerships are changing the landscape. **Lifespan Respite WA**, housed in Aging & Long-Term Support Administration, partnered with WA’s Children with Special Health Care Needs Program to provide respite vouchers to families across ages and disabilities. The **OK Lifespan Respite program** partnered with the state’s Transit Administration to develop mobile respite in the state’s isolated rural areas. States, including NY and NV, are building “no wrong door systems” in partnership with Aging and Disability Resource Centers to improve respite access. States are developing long-term sustainability plans, but without continued federal support, many 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 $20 million in the FY 2020 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. 


