Public Witness Testimony of Jill Kagan, Chair, National Respite Coalition for the Senate Subcommittee on Labor, HHS and Education Appropriations in support of funding for the Lifespan Respite Care Program, FY2021 Administration for Community Living (ACL), Dept. of Health and Human Services
May 22, 2020

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 $10 million for the Lifespan Respite Care Program administered by the Administration on Aging, Administration for Community Living, Department of Health and Human Services, in the FY 2021 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) person and family-centered respite services and information for family caregivers 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 employed 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?** About 41 million unpaid family caregivers of adults provided an estimated 34 billion hours of care — worth $470 billion — to loved ones and friends in 2017 (Reinhard, SC, et al. 2019). 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).

Concerns about providing care for a growing aging population are paramount. However, caregiving is a lifespan issue. The majority (54%) of family caregivers care for someone between the ages of 18 and 75 (NAC and AARP, 2020). The National Children’s Health Survey found the number of children with special health care needs to be close to 14 million (Child and Adolescent...

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, 86% of family caregivers of adults did not receive respite services at all in 2019 (NAC and AARP, 2020). Nearly half of family caregivers of adults (44%) identified in the National Study of Caregiving were providing substantial help with health care tasks, yet, fewer than 17% 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). Parents of children with special health care needs report poorer general health, more physical health problems, worse sleep, and increased depressive symptoms compared to parents of typically developing children (McBean, A, et al., 2013).

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 and narrowly targeted services, cost, and the lack of information about respite or how to find or choose a provider. Moreover, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Lifespan Respite Care Program Helps. The Lifespan Respite Care Program, designed to address these barriers to respite quality, affordability and accessibility, is a competitive grant program to states administered by ACL in the Administration on Aging. The premise behind the program is both care relief and cost effectiveness. Lifespan Respite provides funding to states to expand and enhance local respite services across the country, coordinate community-based respite services to reduce duplication and fragmentation, improve coordination with other community resources, and improve respite access and quality.

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, and $4.1 million in FY 18 and FY 19. We are grateful for the increase to $6.1 million in FY 2020. With these funds, 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.

During the current pandemic, when family caregiver social isolation is escalating, grantees and their primary partners continue to provide respite safely in states where they are permitted to do so. They are the frontline workers who may be the only outside contact and support these families are receiving. If they cannot provide in-person respite, the network has expanded support services to include regular phone call and email check ins, delivery of care packages, online support groups, virtual training and other educational services via Facebook and other social media outlets.

Last year, the House passed the Lifespan Respite Care Reauthorization Act of 2019, introduced by Reps. Jim Langevin (D-RI) and Rep. Cathy McMorris Rodgers (R-WA) With continued bipartisan support, the bill authorizes $200 million over 5 years. The Senate bill, introduced by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI), passed the Senate in February. The Senate bill authorizes $10 annually ($50 million over five years).

How is Lifespan Respite Program Making a Difference? In describing the Lifespan Respite Care Program, a distinguished National Academies of Sciences, Engineering, and Medicine panel 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.” State Lifespan Respite programs are engaged in innovative activities:

- **AL, AR, AZ, CO, DE, MD, MT, ND, NE, NV, NC, OK, RI, SC, TN, VA, WA, and WI**, administer successful self-directed respite vouchers for 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. When families are willing and states permit it, these programs continue to operate during the pandemic.
- **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** and **TN** implemented new volunteer or faith-based respite services.
- 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, Tribal entities and the state’s Traumatic Brain Injury 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 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 $10 million in the FY 2021 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.

*For more information, please contact Jill Kagan, National Respite Coalition at jkagan@archrespite.org or by phone at 703-256-2084.*

**References**


Poster Presentation at the AUCD Annual Meeting, November 2013.


