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 in the FY 2020 Labor/HHS/Education Appropriations Bill
Administration for Community Living (ACL), Dept. of Health and Human Services
May 28, 2019

Mr. Chairman, I am Jill Kagan, Chair, National Respite Coalition (NRC), which is 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 $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. This modest increase 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 Benefits Families**

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). A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry (Spillman and Long, USDHHS, 2007). Additional research has corroborated the role that respite may play in reducing or delaying facility-based placements (Gresham, 2018; Avison, et al., 2018). Respite may reduce administrative burdens and 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). In a survey of caregivers of individuals with Multiple Sclerosis, two-thirds said that respite would help keep their loved one 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 jumped to 75% (NAC, 2012).

With at least two-thirds (66%) of family caregivers in the workforce (Matos, 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 a child with a disability or chronic condition (National Alliance for Caregiving (NAC)). The estimated economic value of family caregiving of adults alone 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 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 of family caregivers caring for someone between the ages of 18 and 75 (53%) (NAC, 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, 2015). Nearly half of family caregivers of adults (44%) identified in the National Study of Caregiving were providing substantial help with health care tasks. Of this group, despite their high level of care, fewer than 17% used respite (Wolff, et al., 2016). A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, Hidden Heroes: America’s Military Caregivers, recommended that more appropriate community-based respite care 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, and many family caregivers rate their caregiving experiences as positive, research shows that family caregivers are at risk for emotional, mental, and physical health problems (Population Reference Bureau, 2016; 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). Despite their higher burden of care, caregivers of persons with dementia are more prone to underutilizing and/or delaying respite. The 2013 Johns Hopkins Maximizing Independence at Home Study, in which researchers surveyed persons with dementia residing at home with their family caregivers, found that nearly half of the caregivers had unmet needs for mental health care and most of these, needed emotional support or respite care (Black,
Respite may not exist at all for children with autism, adults with ALS, MS, spinal cord or traumatic brain injuries, or individuals 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**

The Lifespan Respite Care Program, designed to address these barriers to respite quality, affordability and accessibility, is a competitive grant program administered by the Administration for Community Living (ACL) in its Center for Integrated Programs. 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. Under the program, states are required to establish statewide coordinated Lifespan Respite care systems to serve families regardless of age or special need, provide new planned and emergency respite services, train and recruit respite workers and volunteers, and assist caregivers in gaining access. Family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond basic needs are eligible.

To date, 37 states and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. Many of these states have also received follow on grants to provide or expand direct services, to address the direct care worker shortage by recruiting and training respite workers, to integrate respite into statewide long-term services and support and No Wrong Door systems, to recruit and train respite workers, and to develop long-term sustainability plans.

**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, CO, DE, IL, MD, MT, NE, NV, NC, OK, RI, SC, TN, VA, WI and WA,** have successfully used consumer-directed respite vouchers for serving underserved populations often not eligible for other public programs, including individuals with traumatic brain injury, MS or ALS, adults with intellectual or developmental disabilities (I/DD), children with autism or special medical needs, rural caregivers or those on waiting lists for services.

- States are reporting positive family caregiver outcomes. 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 CO, MA, NC, NY, OH, PA, and SC through mini-grants to community-based agencies, have documented caregiver benefits.

AL, IL, MD, and NE offer emergency respite support and AL, AR, CO, NE, NY, PA, RI, SC and TN are providing new volunteer or faith-based respite services.

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

Partnerships between state agencies are changing the landscape. Lifespan Respite WA, housed in WA’s 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 WA Lifespan Respite grantee also partnered with Tribal entities to provide respite to kinship caregivers. 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/No Wrong Door systems to help family caregivers access respite and funding sources. Funding must be increased to help sustain these innovative state efforts and expand grants to new states. States are developing long-term sustainability plans, but without federal support, many of the grantees will lose funding.

Funding Levels

Congress initially passed the Lifespan Respite Care Program in a bipartisan manner and the program maintains strong, bipartisan support in Congress. The program was authorized at $50 million/year based on the magnitude of our nation’s family caregivers’ needs, but Congress first appropriated only $2.5 million from FY 2009 through FY 2012. The program received slightly less funding in FY13-FY15 due to sequestration. In FY16, given the strong bipartisan support for the program, Congress increased appropriations by $1 million to $3.36 million. This allowed six of the current grantees to receive one-year expansion grants to provide direct services to unserved groups and provided first-time awards to Maryland and Mississippi. For FY 2017, the program was once again funded at $3.36, permitting funding of two new states (ND and SD) and enabling 12 grantees to continue their ground-breaking work to serve more families. An increase in funding to $4.1 million in FY18 and FY19 allowed an additional four states to implement their Lifespan Respite grant activities. In April, the Lifespan Respite Care Reauthorization Act of 2019 was introduced in the House by Reps. Jim Langevin (D-RI) and Rep. Cathy McMorris Rodgers (R-WA) in the Senate by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI). With continued bipartisan support, the bill authorizes $200 million over 5 years.

No other federal program has respite as its sole focus. The Lifespan Respite Care Program is the only federal program that helps ensure respite quality and choice, funds respite start-up, provider recruitment and training, and coordination, and addresses accessibility and affordability issues for families regardless of the care recipient’s age or disability. We urge you to include $20 million in the FY 2020 Labor, HHS, and Education appropriations bill. This is the amount authorized in the newly introduced Lifespan Respite Reauthorization bill. Families will be able to keep loved ones at home, saving Medicaid and other federal programs billions of dollars.

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References


