

**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, FY2024  
Administration for Community Living (ACL), Dept. of Health and Human Services  
May 15, 2023**

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 in the FY 2024 Labor, HHS, and Education Appropriations bill for the Lifespan Respite Care Program administered by the Administration for Community Living, Department of Health and Human Services.** The request reflects prominent recommendations to increase respite care options included in the **National Strategy to Support Family Caregivers** (*Administration for Community Living, 2022*), and will allow all States to receive a Lifespan Respite Grant to help family caregivers, regardless of care recipient's age or disability, access affordable respite. Additional funding will help states improve respite quality; expand the respite workforce; and use person and family-centered approaches that provide family caregivers culturally-competent, tailored information on how to find, use and pay for respite services.

The pandemic cast a harsh light on the lack of supports for the nation's family caregivers. When congregate and group settings became too risky for older adults and people with disabilities, the importance of family caregivers to providing care at home was greatly amplified. At the same time, the availability of services, such as respite, became harder to access and remain so. The Lifespan Respite network responded with flexible respite and support options for family caregivers. During this challenging time, respite may have been the only support family caregivers received. With escalating workforce shortages, new and innovative respite options are even more critical to ensure that family caregivers can continue to provide care at home.

***Respite Care Saves Money and Benefits Families.*** Now, more importantly than ever, 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 records of 28,000 children with autism enrolled in Medicaid 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 reduce caregiver depression, stress and burden linked to caregiver health (*Broady and Aggar, 2017; Lopez-Hartmann, et al., 2012; Zarit, et al., 2014*).

One in five full-time workers are family caregivers (*Rosalyn Carter Institute for Caregivers, 2022*), and at least 60 percent of family caregivers are employed (*Matos, 2015; National Alliance for Caregiving and AARP, 2020*). They often juggle their work and caregiving responsibilities with great difficulty. The impact on employers is significant. Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually (*Witters, 2011*). Family caregivers also experience significant financial burdens that affect their overall wellbeing (*AARP, 2021; National Academies of Sciences, Engineering, and Medicine, 2016*). 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?*** Almost 40 million unpaid family caregivers of adults provide care worth \$600 billion annually (*Reinhard, SC, et al., 2023*); if caregivers of children with special needs are included, the number climbs to 53 million (*National Alliance for Caregiving and AARP, 2020*). 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*). In addition, nearly 14 million children with special health care needs require specialized care from parents and guardians (*Child and Adolescent Health Measurement Initiative, 2022*). Families caring for children with special health care needs provide nearly \$36 billion worth of care annually (*Romley, et al., 2016*).

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 percentage is similar for parents of children with disabilities. The Elizabeth Dole Foundation continues to recommend that respite should be more widely available to military and Veteran caregivers.

***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 (*National Academies of Sciences, Engineering, and Medicine, 2016; 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 or Autism Spectrum Disorder 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 or meaningful service options may prohibit a family from making use of a service they so desperately need.

***Lifespan Respite Care Program Helps.*** The Lifespan Respite Care Program, the only federal program designed to address all of the barriers to respite quality, affordability and accessibility, is a competitive grant program to states administered by ACL. 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 services to reduce duplication and fragmentation, and improve respite access and quality.

The ***National Strategy to Support Family Caregivers*** asserted that an indicator of success in implementing the strategy will be when “family, kin, and grandparent caregivers feel more confident in their ability to provide care because they have a robust array of trained respite options available that are local, convenient, and affordable.” Given its unique mandate, the Lifespan Respite Care Program is the only federal program designed to achieve this goal. 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 for all states and help current grantees complete their ground-breaking work in serving the unserved, and ensuring sustainability by integrating services into statewide No Wrong Door systems for long-term services and supports.

Since 2009, 38 states and DC have received Lifespan Respite grants. We are grateful for the increase in appropriations for the program to \$10 million in FY 2023. However, if we are to achieve the goals of the National Strategy, more funds are necessary.

***How is Lifespan Respite Program Making a Difference?*** Key accomplishments of State Lifespan Respite grantees are highlighted in the ARCH National Respite Network report, [\*In Support of Caregivers\*](#) [[archrespite.org/key-accomplishments](http://archrespite.org/key-accomplishments)]. State Lifespan Respite programs are engaged in the following innovative activities:

- Current and former Lifespan Respite grantees in **AL, AR, AZ, CO, DE, ID, IL, MD, MS, MT, ND, NE, NV, NY, 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.
- **AL, IL, MD, ND, NV** and **NE** offer vouchers for emergency respite.
- **AL's** 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 Network 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, ID, MA, NY, NC, OK, SC** and **WI** through mini-grants to community-based agencies, also have documented benefits

to family caregivers. **AL, AR, CO, NE, NY, RI, SC** and **TN** implemented new volunteer or faith-based respite services with promising results.

- Respite provider recruitment and training are priorities in **AL, AR, IL, MA, MT, NE, NM, NV, NY, SC, SD, 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 **NC, 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.

During the pandemic, social isolation and severe mental health issues among family caregivers intensified. The CDC found that "unpaid adult caregivers reported having experienced disproportionately worse mental health outcomes, increased substance use, and elevated suicidal ideation." The Lifespan Respite network responded with flexible and innovative respite options. For countless caregivers, respite became their only lifeline to supports, services, and vital human connection. **OK, ND, NV, WA, VA, and WI** introduced flexibility in their respite voucher programs, such as expanded eligibility and timeframes, increased flexibility in who could provide respite, and increased voucher amounts. Other Lifespan Respite grantees met the needs of family caregivers through new and creative approaches:

**Alabama:** Alabama Lifespan Respite, in order to increase targeted support to caregivers during the pandemic, introduced a Caregiver Wellness Initiative that increases Emergency Respite reimbursement funds and designates funds specifically for mental health counseling to caregivers currently enrolled with their reimbursement (voucher) program. The intended impacts of the Caregiver Wellness Initiative include decreases in caregiver stress, anxiety, fatigue, and burnout after receiving Emergency Respite and/or mental health counseling.

**Tennessee:** The TN Respite Coalition awarded mini-grants for caregiver-selected items, such as personal protective equipment, tablets enabling internet access to online support groups, home exercise equipment, and movie or magazine subscriptions. Expanding ideas of traditional respite services, the Tennessee Respite Voucher Program provided respite in innovative ways that allowed for safe social distancing but maintained caregiver-provider contact that kept caregivers socially connected during times of increased stress and isolation.

No other federal program has respite as its sole focus, serves family caregivers caring for people of any age or condition, helps ensure respite quality or choice, and supports respite start-up, training or coordination. We urge you to include \$20 million in the FY 2024 Labor, HHS, and Education appropriations bill. The respite goals of the **National Strategy to Support Family Caregivers** will be achieved as families will be able to keep loved ones at home safely and ensure their own well-being, saving Medicaid and other federal programs billions of dollars.

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