

**Public Witness Testimony of Jill Kagan, Chair, National Respite Coalition
for the House Subcommittee on Labor, HHS and Education Appropriations
in support of funding for the Lifespan Respite Care Program, FY2022
Administration for Community Living (ACL), Dept. of Health and Human Services
May 18, 2021**

Madam Chairwoman, 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 \$14.2 million for the Lifespan Respite Care Program in the Administration for Community Living, Department of Health and Human Services, in the FY 2022 Labor, HHS, and Education Appropriations bill.** The increase is consistent with the Administration's request to double funding for the program 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 information on how to find, use and pay for respite services.

The pandemic has 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. The Lifespan Respite network responded with flexible respite options. For countless caregivers, respite became their only lifeline to supports, services, and vital human connection.

Respite Care Saves Money and Benefits Families. Now, more importantly than ever, avoiding a nursing home placement for individuals with Alzheimer's or hospitalization for children with autism can be lifesaving. It can also 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 poor 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*), 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 53 million unpaid family caregivers of adults provide care worth \$470 billion annually (*National Alliance for Caregiving and AARP, 2020; 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*). In addition, nearly 14 million children with special health care needs require specialized care from parents and guardians (*Child and Adolescent*

Health Measurement Initiative, 2021). 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 are not receiving respite services at all** (*NAC and AARP, 2020*), and the percentages are similar for parents caring for children. The Elizabeth Dole Foundation continues to recommend that respite should be more widely available to military 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 (*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 and improve their health and wellbeing, is too often out of reach. In a survey of more than 3000 caregivers of individuals with intellectual and developmental disabilities (ID/DD), 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 mental health issues. 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 provides competitive grants to eligible state agencies. Since 2009, 37 states and DC have received grants. We are grateful for the increase to \$7.1 million in FY 2021; however, the program received no emergency Congressional supplemental funding during the pandemic, despite the elevated need. States are required to establish statewide coordinated 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. A funding level of \$14.2 million would allow all states to receive a grant, help current grantees continue 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? Key accomplishments of State Lifespan Respite grantees are highlighted in a new ARCH National Respite Network report, [*In Support of Caregivers*](#) [archrespite.org/key-accomplishments]. Lifespan Respite grantees 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.

- **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** 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, 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 **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 and need continued federal support to implement them.

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 \$14.2 million in the FY 2022 Labor, HHS, and Education appropriations bill. Families will be able to keep loved ones safely at home, saving Medicaid and other federal programs billions of dollars.

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