

**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, FY2022
Administration for Community Living (ACL), Dept. of Health and Human Services
June 19, 2021**

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 \$14.2 million in the FY 2022 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 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 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. The Lifespan Respite network responded with flexible respite and support options for family caregivers. During this challenging time, this may have been the only support they received.

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 (*Broadly 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 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 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 (*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 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, 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 services to reduce duplication and fragmentation, and improve respite access and quality.

Since 2009, 37 states and DC have received Lifespan Respite grants. The program received \$4.1 million in FY 18 and FY 19, and \$6.1 million in FY 2020. 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. 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 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.

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 check ins, delivery of care packages, online support groups, virtual training and other educational services via Facebook and other social media outlets.

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]. State Lifespan Respite programs are engaged in the following 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 were willing and states allowed it, these programs continued to operate with enhanced flexibilities 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, MD, ND** 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 **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 **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** were some of the states that introduced flexibility to their respite voucher programs to encourage use, such as expanded eligibility and timeframes, increased flexibility in who could provide respite to include other family members in the home, 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, offered Care Chats (one-on-one support by phone or video conferencing) with their social worker staff, monthly support groups, and caregiver mental health education opportunities to help increase overall caregiver wellness. Alabama Lifespan Respite also 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, 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 at home safely and ensure their own well-being, 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

- Alabama Department of Senior Services (2018). *Alabama's Lifespan Respite Sustainability Program Semi-Annual Performance Report, March 30, 2018*. Huntsville, AL: Author.
- American Psychological Association, 2012, Stress in America.
<http://www.apa.org/news/press/releases/stress/2011/health-risk.aspx>
- American Psychological Association (nd). *Caregiver Briefcase: Family Caregiver Well-Being is Important to Care Recipient Health*.
<http://www.apa.org/pi/about/publications/caregivers/faq/well-being.aspx>
- Anderson, L., Hewitt, A., Pettingell, S., Lulinski, A., Taylor, M., & Reagan, J. (2018) *Family and Individual Needs for Disability Supports (v.2) Community Report 2017*. Minnesota: Research and Training. Center on Community Living, Institute on Community Integration, University of Minnesota. <https://www.thearc.org/FINDS>
- Avison, C, Brock, D, Campione, J, Hasell, S, Rabinovich, B, Ritter, R, Severynse, J, Yang, D-H (2018) *Final Report prepared for the U.S. Administration for Community Living: Outcome Evaluation of the National Family Caregiver Support Program*. Washington, D.C.: Westat.
- Black, BS, PhD; Johnston, D MB, Rabins, PV, MD, MPH, Morrison, A PhD, RN, Lyketsos, C MD, MHS, and Samus, QM, PhD, Unmet Needs of Community-Residing Persons with Dementia and Their Informal Caregivers: Findings from the Maximizing Independence at Home Study. *Journal of the American Geriatrics Society*, Volume 61, Issue 12, pages 2087–2095, December 2013.
- Broady, T. and Aggar, C. (2017). Carer interventions: An overview of service effectiveness. *J of the Australasian Rehabilitation Nurses' Association*, 20 (2), 5-11.
- Caldwell, J. (2007). Experiences of families with relatives with intellectual and developmental disabilities in a consumer-directed support program. *Disability and Society*, 549-562.
- Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by the U.S. Department of Health and Human Services, Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB). Retrieved [05/09/2021] from <https://www.childhealthdata.org/browse/survey/results?q=7687&r=1>.
- Congressional Budget Office (2013). *Rising Demand for Long-Term Services and Supports for Elderly People*. Washington, DC: Author <https://www.cbo.gov/publication/44363>
- Gresham M., Heffernan, M., and Brodaty, H. (2018). The Going to Stay at Home program: combining dementia caregiver training and residential respite care. *International Psychogeriatrics*, 1-10.

- Harper, A; Dyches, TT; Harper, J; Roper, SO; and South, M. (2013). Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, March 2013.
- Johnson, J., Swanson, S., and Falk, K. (2018). *Nebraska Lifespan Respite Network: Producing Positive Outcomes for Families, 2015-2017*. Munroe-Meyer Institute and the Interdisciplinary Center of Program Evaluation, University of Nebraska Medical Center.
- Kirk, R, PhD (2015). *A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders*. Chapel Hill, NC: ARCH National Respite Network and Resource Center.
http://archrespite.org/images/docs/2015_Reports/ARCH_Respite_Research_Report_web.pdf
- Lopez-Hartmann, M., Wens, J., Verhoeven, V., and Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers or community-dwelling frail elderly: a systematic review. *International Journal of Integrated Care*, 12: 1-14.
- Mandell, David S. ScD; Xie, Ming, MS; Morales, Knashawn H., ScD; Lawer, Lindsay, MA; McCarthy, Megan, MA; Marcus, Steven C., PhD. (2012). The Interplay of Outpatient Services and Psychiatric Hospitalization among Medicaid-Enrolled Children with Autism Spectrum Disorders. *Arch Pediatr Adolesc Med*. 2012;166(1):68-73.
- Maryland Caregivers Support Coordinating Council, MD Department of Human Resources (2015). *Understanding Caregiver Needs in Maryland -- Summary of Key Findings: Caregiver Survey Maryland 2015*.
- Matos, K. (2015). Highlights from the 2014 Older Adult Caregiver Study. New York, NY: Families and Work Institute. <http://www.familiesandwork.org/downloads/2014-Older-Adult-Caregiver-Study.pdf>
- McBean, Amanda L. and Schlosnagle, Leo (2013). *Relations between Sleep Disturbance, General Health, and Memory among Parents of Children with Special Health Care Needs*. Poster Presentation at the AUCD Annual Meeting, November 2013.
- MetLife Mature Market Institute. (2006). *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*. <https://www.metlife.com/assets/cao/mmi/publications/studies/mmi-caregiver-cost-study-productivity.pdf>
- National Academies of Sciences, Engineering, and Medicine (2016). *Families Caring for an Aging America*. Washington, DC: The National Academies Press.
- National Alliance for Caregiving and AARP Public Policy Institute (2020). *Caregiving in the U.S. 2020*. Washington, DC: Authors. <https://www.caregiving.org/caregiving-in-the-us-2020/>
- National Alliance for Caregiving. (2012). *Multiple Sclerosis Caregivers*. Washington, DC: Author. http://www.caregiving.org/pdf/research/MSCaregivers2012_FINAL.pdf
- Population Reference Bureau. Family Caregiving. *Today's Research on Aging*, No. 33, February 2016. <http://www.prb.org/pdf16/TodaysResearchAging33.pdf>

Ramchand, R, Tanielian, T, Fisher, MP, Vaughan, CA, Trail, TE, Epley, C; Voorhies, P, Robbins, M, Robinson, R, Ghosh-Dastidar, B (2014). *Hidden Heroes: America's Military Caregivers*. Santa Monica, CA: The Rand Corporation.

http://www.rand.org/pubs/research_reports/RR499.html

Reinhard, SC, Feinberg, L, Choula, R, Houser, A and Evans, M (2019). Valuing the Invaluable: 2019 Update -Charting a Path Forward. Washington, DC: AARP Public Policy Institute.

<https://doi.org/10.26419/ppi.00082.001>

Romley, JA, Shah, AK, Chung, PJ, Elliott, MN, Vestal, KD, and Schuster, MA (2016). Family-Provided Health Care for Children with Special Health Care Needs. *Pediatrics* December 2016, e20161287; DOI: <https://doi.org/10.1542/peds.2016-1287>

Spillman, Brenda C, and Long, S, prepared for the USDHHS (U.S. Department of Health and Human Services). (2007). *Does high caregiver stress lead to nursing home entry?* Washington, DC: Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-term Care Policy. January 26, 2007 DHHS Report. <https://aspe.hhs.gov/basic-report/does-high-caregiver-stress-lead-nursing-home-entry>

Spillman, BC, J Wolff, VA Freedman, and JD Kasper. *Informal Caregiving for Older Americans: An Analysis of the 2011 National Survey of Caregiving*. Report to the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long-Term Care Policy, April 2014. <https://aspe.hhs.gov/report/informal-caregiving-older-americans-analysis-2011-national-study-caregiving>

Wolff, JL; Spillman, BC; Freedman, VA; and Kasper, JD (2016). A National Profile of Family and Unpaid Caregivers Who Assist Older Adults with Health Care Activities. *JAMA Intern Med*. 2016; 176(3):372-379.

Witters, Dan. The Cost of Caregiving to the U.S. Economy. *Gallup Business Journal*, December 2011. <http://businessjournal.gallup.com/content/151049/Cost-Caregiving-Economy.aspx>

Zarit, S.H., Whetzel, C.A., Kim, K., Femia, E.E., Almeida, D.M., Rovine, M.J., Klein, L.C. (2014). Daily Stressors and Adult Day Service Use by Family Caregivers: Effects on Depressive Symptoms, Positive Mood, and Dehydroepiandrosterone-Sulfate. *Am J Geriatr Psychiatry*.