

Lifespan Respite Care Program
RAISE Family Caregiving Advisory Council's National Family Caregiver Strategy
Policy Recommendations for the Presidential Transition and the 117th Congress
ARCH National Respite Coalition
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Family Caregivers are the Linchpin of the Nation's Long-Term Services and Supports System

In the first 100 days, the Administration should commit to ensuring the RAISE Family Caregiving Advisory Council's recommendations for a national family caregiver strategy are meaningful and address the needs of caregivers of both children and adults. The Administration should also commit the U.S. Department of Health and Human Services to oversee the full and swift implementation of the proposed strategy. The very successful Lifespan Respite Care Program that addresses the needs of all caregiving populations should be fully funded as the cornerstone of the national family caregiving strategy.

With 53 million family caregivers providing care to family members and friends, the nation cannot ignore their increasing need for support. With changing demographics escalating the need for affordable long-term care, and a shortage in the direct service workforce, we will continue to rely on family members to provide this care. The pandemic has put enormous strain on state budgets and has contributed to increased reliance on family caregivers to provide care. At the same time, the pandemic has exacerbated the social isolation and economic insecurity already experienced by caregivers and their loved ones and the devastating effects on their health and wellness. At the same time, the pandemic has helped raise awareness of their tremendous needs. For many, respite may be their only connection to services and supports they so desperately need.

Early in 2021, the Administration for Community Living's RAISE Family Caregiving Advisory Council is expected to issue final recommendations for a national strategy for family caregivers, including ways to ensure that the public and private sectors work to ensure respite services are available, affordable and of high quality. We call on the new Administration to commit to enabling strong and meaningful recommendations to emerge from the council with a commitment to ensure full implementation of a national strategy to support family caregivers.

Respite Care Saves Money and Benefits Families. Even before the pandemic, delaying a nursing home placement for individuals with Alzheimer's or avoiding hospitalization for children with autism was found to 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*).

More than 50 million family caregivers are providing care for individuals of all ages. While the growing older population is driving the demographics of caregiving, the majority of family caregivers (54%) care for someone 18 to 75 years of age (*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 Health Measurement Initiative, 2020*). Families caring for children with special health care needs provide nearly \$36 billion worth of care annually (*Romley, et al., 2016*).

Approximately 1.1 million grandparents (age 60+) were responsible for the basic needs of one or more grandchildren under age 18 living with them in 2018, and one in ten U.S. parents of children in the “sandwich” generation also care for an adult (*U.S. Department of Health and Human Services, 2020; Livingston, 2018; National Alliance for Caregiving, 2019*). Eighty percent of individuals with I/DD live with a caregiver who is their family member (*Anderson, L, et al., 2018*). Almost 25% of the 3.6 million adults with intellectual/development disabilities (I/DD) lived with a family caregiver who is over age 60 (*Braddock, D, et al., 2017*).

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*), all made worse by the pandemic. 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 respite include cost, limited public resources or long waiting lists, reluctance of family caregivers to ask for help, mistrust of service systems, lack of information about how to access respite, and limited self-identification among family caregivers leading to lack of awareness about available supports. Most noteworthy among the barriers to respite use is the extremely limited supply of well-qualified respite providers or preferred respite options. The short and long-term effects of the COVID-19 pandemic may seriously exacerbate these barriers.

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 the Administration for Community Living in the Administration on Aging. It should be the cornerstone of any national family caregiving strategy. It is the only federal caregiving program focused on the needs of caregivers who provide care to individuals of all ages, disabilities, and chronic conditions, especially those who do not qualify for other publicly funded services. It is the only federal caregiving program that addresses respite capacity by allowing start-up funding of community, volunteer and faith-based services. It is the only federal caregiving program addressing the provider workforce crisis by requiring that states recruit and train new respite providers and volunteers.

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. Despite the breadth of the population the program is expected to serve and its focus on serving those who do not qualify for any other public funding sources, the Lifespan Respite Care Program received no supplemental funding in COVID-19 relief legislation, leaving large numbers of newly engaged family caregivers with very limited or no respite options.

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. Many have instituted expanded respite voucher program eligibility, introduced flexibility in who can provide respite, instituted safety protocols that meet CDC and state public health standards, and increased respite hours to make sure that families can use and benefit from the service. Respite providers 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 Lifespan Respite grantees have 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.

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 million annually (\$50 million over five years). We expect this version of the bill to be enacted before the end of the current Congress. If it is not, we call on the Administration to support the swift reauthorization of the Lifespan Respite Care Program when reintroduced in the new Congress.

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. For more information on State Lifespan Respite Program grantee accomplishments, please see [State Lifespan Respite Grant Objectives, Outcomes and Activities](https://archrespite.org/lifespan-programs/state-lifespan-respite-grantee-activities) [<https://archrespite.org/lifespan-programs/state-lifespan-respite-grantee-activities>].

No other federal program has respite as its sole focus, helps ensure respite quality or choice, and supports respite start-up, training and coordination. We urge the incoming Administration to support full funding (\$10 million) for Lifespan Respite in the in its proposed budget for FY 2022. Families will be able to keep loved ones at home, saving Medicaid and other federal programs billions of dollars.

Most importantly, the Administration should commit to meaningful recommendations from the RAISE Family Caregiving Advisory Council for a national family caregiving strategy with a promise of full and swift implementation.

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