

**Recommendations Submitted to the RAISE Family Caregiver Council
by the ARCH National Respite Coalition
The policy division of the ARCH National Respite Network
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National, State and local surveys have shown respite to be among the most frequently requested services by family caregivers. **Yet, 85% of family caregivers of adults are not receiving respite services at all and the percentage is similar for parents caring for children with special needs.** Another study found a similar result. 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.

Respite has been shown to ease family caregiver stress which can impact their health and well-being. The recent national evaluation of the National Family Caregiver Support Program (NFCSP) found that NFCSP caregivers who received 4 or more hours of respite care per week had a decrease in self-reported burden over time, while the comparison caregivers experienced an increase in self-reported burden. In addition, among caregivers who used NFCSP respite care, as the respite hours per week increased, so did the probability of a more favorable response regarding caregivers' perception that services helped them continue caregiving. In the National Caregiver Respite Study conducted for the Corporation for National and Community Service, 60% of caregivers with critical needs reported that Senior Companion respite services helped them "a lot" or a "great deal" and allowed them to be more involved in social activities and enjoy time with their friends or relatives. Approximately 40% of caregivers who rated their health as fair or poor before respite support, rated their health as good at a one-year follow-up point.

Despite the benefits, respite 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), 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. Despite their higher burden of care, caregivers of persons with dementia are more prone to underutilizing and/or delaying respite. Respite may not exist at all for children or adults with mental health conditions, adults with ALS or MS, or individuals with spinal cord or traumatic brain injuries.

Barriers to accessing respite include fragmented and narrowly targeted services; restrictive eligibility criteria for many publicly funded programs; limited respite options, especially for extended or overnight care or respite; 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.

The Lifespan Respite Care Program, designed to address barriers to respite quality, affordability and accessibility, is a competitive grant program administered by the

Administration for Community Living (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; reduce duplication and fragmentation; improve coordination with other community and state 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.

To date, 37 states and the District of Columbia have received grants to build coordinated systems of community-based respite services. Many of these states have also received follow on grants to provide or expand critical gap-filling respite assistance for family caregivers who don't qualify for public funding sources or are on waiting lists; 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; and to develop long-term sustainability plans. In addition, states have funded innovative models to enhance respite capacity through community-based agencies and volunteer and faith-based initiatives. For families who don't qualify for publicly funded formal services or are hesitant to use them, Lifespan Respite projects work with families to identify and plan for informal respite options within their systems of natural family and community supports.

While program funding has severely limited the Lifespan Respite Care Program's capacity to reach large numbers of family caregivers in need, the program has demonstrated an exceptional strategy for building partnerships and expanding and enhancing person and family-centered respite services. The Lifespan Respite Care program should serve as a model for a national respite strategy to meet the needs of family caregivers caring for anyone of any age or condition.

Other federal programs. In addition, other federal programs that have the potential to support respite in the **child welfare, aging and disabilities, public health, early intervention and mental health services systems** should be encouraged and supported by federal and state government agencies to do so. **Medicaid home and community-based waivers** are currently the largest source of federal funding for respite, yet waiting lists remain long and have increased in 23 states since 2017. The federal government should work with states to reduce and eliminate waiting lists and increase Medicaid reimbursement rates to states to address the direct service worker shortage, a crisis contributing to the expansion of waiting lists.

Moreover, as states transition long-term services and support(LTSS) from fee-for-service to **managed care for Medicaid populations**, families are fearful that supports such as respite could disappear. Managed care organizations should provide assurances that respite will be included as a benefit in all state contracts. As States negotiate contracts with MCOs for LTSS benefits, Lifespan Respite grantees, state respite coalitions, and family caregivers should be at

the table to inform the process. At the federal and state levels, implementing better and more uniform data collection on the extent and type of respite provided by Medicaid waivers would help justify the need and the cost-benefits.

For the Medicare population, CMS has issued regulations permitting **Medicare Advantage plans** to provide respite and adult day services. These plans should be educated on the benefits of respite, including the importance of respite to improving caregiver health and well-being, helping to reduce hospital readmissions, and other cost-benefits. Finally, to maximize family choice, respite provided under the **Medicare and Medicaid hospice** benefits should allow respite to be provided in-home rather than solely in facilities and hospitals.

Building on research summits hosted by the National Institute on Aging for Dementia Care, ACL should convene the National Institutes of Health, including NIA, NICHD and NIMH, academic, other research entities, and private funders. The aim would be to encourage **respite research that advances the evidence base for respite** to ensure long-term sustainability and continuous quality improvement.

Private sector. In the private sector, **employers** should be educated and encouraged to offer respite services and information to the more than 60% of family caregivers who are working. Incentives should be provided for **private insurers**, including Medicare Advantage Plans, to offer respite as a covered benefit. Therefore, we recommend that ACL convene a roundtable of business and health insurance leaders to explore opportunities for and barriers for achieving these policy changes.