



**Lifespan Respite Care Program**  
**Policy Recommendations for the Presidential Transition and the 115th Congress**  
**Supported by the ARCH National Respite Coalition and 37 National Partners**  
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**What is Respite Care?**

Taking care of a family member or friend who has a chronic illness or disability can be enormously rewarding—but it can be physically and emotionally draining as well. That’s why it’s important for family caregivers to seek occasional respite from their caregiving responsibilities. Respite care provides temporary relief for family caregivers from the ongoing responsibility of caring for an individual of any age with special needs—while the person with special needs continues to receive care in a safe environment. As a preventive strategy, respite helps strengthen families, protects their health and well-being, may help avoid or delay institutionalization and allow family caregivers to continue providing care at home. Respite is an important component of a continuum of care and support, not only on a planned basis, but also in the event of a crisis or emergency situation.

**The Lifespan Respite Care Program**

The Lifespan Respite Care Program is a competitive grant program administered by the Administration for Community Living (ACL), in its Center for Integrated Programs. The premise behind the program is both care relief and cost effectiveness, so 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 to improve respite access and quality. Under the program, states are required to establish state and local 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. Those eligible include family members, foster parents or other adults providing unpaid care to adults who require care to meet basic needs or prevent injury and to children who require care beyond basic needs.

To date, 35 states and the District of Columbia have received basic grants to build coordinated systems of community-based respite services. Most of these states have also received follow on grants to provide or expand direct services, to help integrate services and grant activities into statewide long-term services and support systems, and to develop long-term sustainability plans.

**Respite Care Saves Money and is it Helpful to the People it Serves**

Compelling budgetary benefits accrue because of respite. Delaying a nursing home placement for one

person with Alzheimer's or avoiding hospitalization for a child with autism can save Medicaid and other government programs thousands of dollars. Researchers at the University of Pennsylvania studied the records of 28,000 children with autism enrolled in Medicaid in 2004. They concluded that for every \$1,000 states spent on respite, there was an 8% drop in the odds of hospitalization. Respite may reduce administrative burdens and reduce facility-based placements, and can improve maternal employment. With at least two-thirds (66%) of family caregivers in the workforce, private sector costs also must be taken into account. U.S. businesses lose from \$17.1 to \$33.6 billion per year in lost productivity of family caregivers. Higher absenteeism among working caregivers costs the U.S. economy an estimated \$25.2 billion annually. Respite for working family caregivers could improve job performance, saving employers billions.

Respite helps avoid or delay out-of-home placements, minimizes precursors that can lead to abuse and neglect, and strengthens marriages and family stability. These findings were recently corroborated by a review of the literature conducted by an Expert Panel on Respite Research, convened by ARCH with support from ACL. For example, a study of parents of children with autism found that respite was associated with reduced stress and improved marital quality. A U.S. Department of Health and Human Services report found that reducing key stresses on caregivers through services such as respite would reduce nursing home entry. In a survey of caregivers of individuals with MS, two-thirds said that respite would help keep their loved one at home. When the care recipient with MS also has cognitive impairment, the percentage of those saying respite would be helpful to avoid or delay nursing home placement jumps to 75%.

Respite has been shown to help reduce stress among family caregivers. Managing stress among caregivers is important because high levels of stress are often precursors to developing significant physical and mental health issues. New studies of adult day services use for respite are demonstrating the relationship between reduced stress and the potential for enhanced long-term health outcomes. In an integrative review of 19 studies, it was found that day care centers for people with dementia as a respite and support services, have "the potential to give family caregivers a feeling of safety and relief, reduce the caregiver's burden, and increase their motivation towards their role as caregivers."

### **Impact of the Lifespan Respite Care Program**

In describing the Lifespan Respite Care Program, a distinguished panel of experts from the National Academies of Sciences, Engineering, and Medicine recently 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." Despite limited funds, Lifespan Respite grantees are engaged in innovative activities in the public and private sectors to improve access to respite services and address serious service gaps for the millions of underserved and unserved populations of family caregivers. Some examples are:

- **Alabama, Arizona, Delaware, Montana, Nebraska, Nevada, North Carolina, Oklahoma, Rhode Island, South Carolina, Tennessee, Virginia, and Washington** have successfully used consumer-directed respite vouchers for serving underserved populations, such as individuals with MS or ALS, adults with intellectual or developmental disabilities (I/DD), or those on waiting lists for services.
- **Idaho, Illinois, Iowa, and Nebraska** offer emergency respite support.

- **Alabama, Arizona, Colorado, Massachusetts, Nebraska, New York, Ohio, Pennsylvania, South Carolina and Tennessee** are providing new and innovative volunteer and faith-based respite initiatives.
- Innovative and sustainable respite services, funded in **Colorado, Massachusetts, North Carolina and Ohio** through mini-grants to community-based agencies, have documented benefits to family caregivers.
- Respite provider recruitment and training are priorities in **Arkansas, Nebraska, New Hampshire, Virginia, and Wisconsin**.

Additional partnerships between state agencies are changing the landscape. The AZ Lifespan Respite program housed in Aging and Adult Services partnered with AZ’s Children with Special Health Care Needs Program to provide respite vouchers to families across the age and disability spectrum. The OK Lifespan Respite program partnered with the state’s Transit Administration to develop mobile respite to serve isolated rural areas of the state. States are building respite registries and “no wrong door systems” in partnership with Aging and Disability Resource Centers to help family caregivers access respite and funding sources. Funding must be maintained to help sustain these innovative state efforts. States are developing long-term sustainability plans, but without federal support, many of the grantees will be cut.

### **Funding Levels**

Congress initially passed the Lifespan Respite Care Program in a bipartisan manner and the program maintains strong, bipartisan support in Congress. The program was authorized at \$50 million/year based on the magnitude of our nation’s family caregivers’ needs, but Congress first appropriated funds for the program in FY 2009 at \$2.5 million, and continued to fund the program at this level through FY 2012. The program received slightly less funding in FY13-FY15 due to sequestration. In FY 2016, given the strong bipartisan support for the program, Congress increased appropriations by \$1 million to \$3.36 million. This allowed six of the current grantees to receive one-year expansion grants to provide direct services to unserved groups, and allowed Maryland and Mississippi to receive first-time awards. For FY 2017, the House recommended increasing the appropriation to \$4 million, while the Senate recommended level funding. Additional funds would allow grants to be made to several new states and would help current grantees complete their ground-breaking work.

**No other federal program has respite as its sole focus.** The Lifespan Respite Care Program is the only federal program that helps ensure respite quality and choice, allows funds for respite start-up, training and coordination, and addresses basic accessibility and affordability issues for families regardless of age or disability issues.

### **What could the Administration Accomplish for Lifespan Respite Care in its First 100 Days?**

**We urge the incoming Administration and Congress to consider the following recommendations for the first 100 days:**

- **Encourage and support, at a minimum, current funding levels for Lifespan Respite in the final FY 2017 Labor, HHS, and Education appropriations bill—\$3.36 million.**

- **The President’s proposed budget for FY 2018 should include at least \$5 million for the Lifespan Respite Care Program.**
- **The Administration should support, and Congress should enact, the reauthorization of the Lifespan Respite Care Program at \$15 million annually through FY 2021. The current Lifespan Respite Care Reauthorization bill (HR 3913), pending in the 114<sup>th</sup> Congress, was introduced by Rep. Gregg Harper (R-MS) and Rep. Jim Langevin (D-RI) and has 24 cosponsors from both parties.**

Such actions will enable:

- States to maximize use of current resources, leverage private sector funds, and reduce state and local bureaucracy by coordinating and streamlining existing respite funding streams and services;
- State implementation of best practices in Lifespan Respite systems so that family caregivers will have access to affordable respite, and will be able to continue to play the significant role that they are fulfilling today, saving Medicaid and other public programs billions of dollars;
- Continued development of quality respite services;
- Expansion of respite program capacity for unserved families through development of formal, faith-based, and volunteer respite care options, including recruitment and training of respite workers and volunteers; and
- Greater consumer direction by providing family caregivers with training and information on how to find, use and pay for respite services.

### **Who are America’s Family Caregivers?**

In 2013, about 40 million family caregivers in the United States provided an estimated 37 billion hours of care to an adult with limitations in daily activities. While there is a profile of a typical caregiver, caregivers on the whole are becoming as diverse as the American population and include more men and younger "millennial" caregivers. Family caregivers save the government a tremendous amount of money. It has been estimated that family caregivers of adults provide \$470 billion in uncompensated care, an amount that is more than total Medicaid spending in 2013, including both federal and state contributions for both health care and long-term services and supports (LTSS) at \$449 billion.

A Rand Corporation study relying on data from the American Time Use Survey estimated the value of informal caregiving in the U.S. by friends and relatives of the aging at \$522 billion a year. Replacing that care with unskilled paid care at minimum wage would cost \$221 billion, while replacing it with skilled nursing care would cost \$642 billion annually. By properly supporting family caregivers through nominal spending and supports like respite care, family caregivers can continue to save the government tremendously (see also Respite Care Saves Money and is Helpful to the People it Serves section on pages

1-2).

Eighty percent of those needing LTSS are living at home. In 2013, the Congressional Budget Office estimated that two out of three (66%) older people with disabilities who receive LTSS at home get all their care exclusively from family caregivers. This percentage will only rise in the coming decades with greater life expectancies of individuals with disabling and chronic conditions living at home with their aging parents or other caregivers, the aging of the baby boom generation, the decline in the percentage of the frail elderly who are entering nursing homes, and the trend toward home and community-based living for people with disabilities of all ages.

Immediate concerns about how to provide care for a growing aging population are paramount. However, caregiving is a lifespan issue with the majority of family caregivers caring for adults between the ages of 18 and 75 (53%) with conditions such as MS, ALS, paralysis, traumatic brain injury, cancer, mental health issues, early onset Alzheimer's disease, cancer, and other chronic conditions. These populations have the most difficult time accessing supports, such as respite, because of restrictive program eligibility, too few respite options, or not enough well-trained providers who meet their special needs.

In addition, close to 14.6 million children under 18 were identified as having a special health care need in 2012. The federal Maternal and Child Health Bureau defines children with special health care needs as: "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally." A previous estimate of the value of uncompensated care for 4 to 8 million caregivers of children with special needs added \$50 to \$100 billion to the economic value of family caregiving.

### **The Demand for Respite, and Current Barriers to Access**

While most families want to care for family members at home, and many family caregivers rate their caregiving experiences as positive, research shows that family caregivers are at risk for serious emotional stress and mental and physical health problems. 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 abuse from caregivers among care recipients with significant needs increases when caregivers themselves are depressed or in poor health. 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.

### **National, State and local surveys have shown respite to be the most frequently requested service by family caregivers. Yet, 85% of family caregivers of adults are not receiving respite services at all.**

The percentage is almost equally as high among parents caring for a child with a disability. 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. Another study found that in rural areas, the percentage of family caregivers able to make use of respite was only 4%.

Caregivers providing higher hours of care are more likely to say respite services would be helpful. Respite services are especially appealing to higher-hour caregivers who live with their care receiver. Other than

financial assistance for caregiving through direct voucher payments or tax credits, respite has been identified as the most important national policy related to service delivery by family caregivers.

Barriers to accessing respite include reluctance to ask for help, fragmented and narrowly targeted services, feelings of social isolation, lack of respite options, cost, and the lack of information about how to find or choose a provider. Some federal programs that pay for respite, such as the 1915(c) Home and Community Based Services Medicaid Waivers and the National Family Caregiver Support Program only meet the needs of a small percentage of family caregivers who would benefit from respite and other family caregiver supports. A 2012 Institute of Medicine report documented that caregivers believe that not enough respite is available. As a result, even when respite funding is available for families, a critically short supply of well-trained respite providers may prohibit a family from making use of a service they so desperately need.

Restrictive eligibility criteria preclude many families from receiving services. For example, many children with disabilities age out of the system when they turn 21 and lose services, such as respite. A survey of nearly 5000 caregivers of individuals with intellectual and developmental disabilities (I/DD) found the vast majority of caregivers report physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%); 1 out of 5 families (20%) report that someone in the family quit their job to provide care; and more than 75% of family caregivers could not find respite services.

Families of children and adolescents with serious emotional or medical conditions, physical disabilities, or autism may have an especially difficult time finding respite. According to the most recent National Survey of Children with Special Health Care Needs, half of children whose families reported a need for respite care did not receive it. In addition, more than 2.5 million children are raised by grandparents and other relatives or close family friends when parents are unable to do so. Grandparents and other relative caregivers save taxpayers \$4 billion each year by keeping these children out of foster care. Supporting grandfamilies with services such as respite that allow them to continue providing this care makes economic sense. Children are even serving in caregiving roles. Nationwide, approximately 1.3 to 1.4 million child caregivers between the ages of 8-18 are providing care to their parents, grandparents or siblings; 25% are providing this care on their own. The effects of caregiving on this population have been well documented, yet very few respite options exist for this group.

Families of the wounded warriors, military personnel who returned from Iraq and Afghanistan with traumatic brain injuries and other serious chronic and debilitating conditions, don't have full access to respite. Even with enactment of the VA Family Caregiver Support Program, which has served post-9/11 Veterans, the need for respite remains high. A 2014 Rand Corporation report prepared for the Elizabeth Dole Foundation, *Hidden Heroes: America's Military Caregivers*, recommended that respite care should be more widely available to military caregivers. The Dole Foundation's Respite Impact Council found that traditional respite services do not address the needs of military caregivers and the Lifespan Respite Care program should be fully funded to help meet those needs.

## **Conclusion**

With tens of millions of families affected, **caregiving is a public health issue requiring an immediate proven preventive response, such as respite care.** We urge you to include funds in the final FY 2017 Labor, HHS, and Education appropriations bill, reauthorize the program in a timely way, and provide

increases in FY 2018 that will allow additional states to receive a grant and assist best practices in current Lifespan Respite Programs to be implemented and sustained. Families, with access to respite, will be able to keep their loved ones at home, saving Medicaid and other federal programs, billions of dollars.

**We would be honored to serve as a resource on respite care for the Administration. For questions about this memo, or for more information, please contact Jill Kagan, National Respite Coalition at [jkagan@archrespite.org](mailto:jkagan@archrespite.org) or by phone at 703-256-2084.**

Thank you for considering our recommendations, and we look forward to working with you to enhance the health and well-being of America's family caregivers.

**Supported by:**

**Alliance for Aging Research  
Alzheimer's Foundation of America  
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American Music Therapy Association  
American Psychological Association  
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National Alliance for Caregiving  
National Alliance of Children's Trust & Prevention Funds  
National Association for Home Care & Hospice  
National Association of Councils on Developmental Disabilities  
National Association of Social Workers (NASW)  
National Association of State Directors of Developmental Disabilities Services  
National Association of State Directors of Special Education  
National Down Syndrome Congress  
National Military Family Association  
National Multiple Sclerosis Society  
National Respite Coalition  
OWL- The Voice of Women 40+  
Paralyzed Veterans of America  
The Arc**

**The ALS Association**  
**The Michael J. Fox Foundation**  
**United Cerebral Palsy**  
**United Spinal Association**  
**Well Spouse Association**

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**About the Lifespan Respite Task Force of the ARCH National Respite Network and Resource Center**

The ARCH National Respite Network and Resource Center (ARCH) is a network of state Lifespan Respite grantees, respite providers, family caregivers, and representatives of additional state and local agencies and organizations across the country who support respite. The Resource Center provides training and technical assistance to the network. More than thirty state respite coalitions are also affiliated with ARCH. The National Respite Coalition (NRC) is the policy division of ARCH. NRC's mission is to secure quality, accessible, planned and crisis respite services for all families and caregivers in need of such services in order to strengthen and stabilize families, and enhance child and adult safety. The Coalition works to achieve these goals by preserving and promoting respite in policy and programs at the national, state, and local levels.

The NRC facilitates the Lifespan Respite Task Force, a coalition of over 50 national organizations supporting the funding and reauthorization of the Lifespan Respite Care Act. The Lifespan Respite Task Force, established in 2000, was a major force in passing the Lifespan Respite Act of 2006 and continues to serve to ensure continued funding for the program and to help oversee program implementation. This transition brief is presented on behalf of the NRC as well as the national organizations of the Lifespan Respite Task Force listed above which have signed on in support of these recommendations.

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