Preface

Respite services were first created more than 40 years ago. As the trend toward home and community-based services continues and more and more families are caring for an aging family member or a family member with a disability or chronic condition in their homes, the nation also has begun to shift its strategy for long-term services and supports away from facilities and toward the home and community. Home and community-based services are preferred by most families, and many of these services, such as respite, are less expensive than facility-based living. However, if family caregivers are to continue to assume the responsibility for providing the bulk of long-term services and supports, they must receive support. When asked what kind of help they need, family caregivers frequently say, “I need a break.”

During this same period, there has been an increasing awareness of families who are experiencing a crisis or whose children or dependent adult family members are at risk of abuse or neglect. When the child or dependent adult who is at risk can be cared for temporarily by a trusted adult outside the family, often the family’s situation can be stabilized so the person at risk can safely return to the family’s care. This kind of temporary care is known as crisis care or emergency respite.

Respite can help family caregivers provide the care and nurturing that dependent family members need, meet the needs of other family members, ensure their own health and well-being, and participate normally in community life. When the need for a break from continuous care goes unmet, stress may build, potentially leading to adverse consequences, such as poor family caregiver health and well-being, abuse, neglect, divorce, or out-of-home placements.

The Lifespan Respite Care Program provides grants to states to establish or enhance Lifespan Respite systems, which are defined by law as “coordinated systems of community-based respite for family caregivers of children or adults with special needs.” Such systems are, to a large extent, dependent on existing state and federal funding streams for respite, which are often limited by restrictive age or disability eligibility criteria, family income, or circumstance. These disparate funding streams may result in programs with long waiting lists or create a bureaucratic maze difficult for families to navigate. The purpose of the Lifespan Respite Care Program is to expand and enhance respite care services; to improve statewide dissemination and coordination of respite care; and to provide, supplement, or improve access to and quality of respite care services.

Potential funding authorization for respite services can be found in many federal statutes or program directives. However, this should in no way be interpreted as providing enough support for respite for the nation’s family caregivers. The emphasis should be on the word “potential.” Although respite is not specifically mandated by any of these statutes, it may be listed as one of the many family caregiver support services that are eligible for funding. In some cases, support for respite is only implied under the larger headings of home and community-based services or family support. In most cases, the authority to decide whether to fund respite and/or crisis care services with these federal resources has been given to state, regional, or local governments. No national data exist regarding how much federal funding is actually being spent on all respite and crisis care services for all ages. In fact, given the limited availability of respite services, long waiting lists for respite, and small percentages of family caregivers who use respite, it is believed that a relatively small proportion of federal funds is invested in respite and crisis care. The most recent survey of family caregivers conducted by the National Alliance for Caregiving and the AARP Policy Institute found that of the 43 million family caregivers
nationwide, 85% were not receiving respite.\(^1\) Inadequate use of these potential funding sources could be due to lack of awareness about these federal programs and their potential for funding respite and crisis care services, competition for scarce resources, especially in these times of serious budgetary challenges, or limited knowledge about the benefits that investments in respite and crisis care programs can bestow.

Lifespan Respite systems are meant to help states identify existing or potential respite funding sources within their own states, better coordinate these funding streams and maximize their use, and reduce the state’s administrative expenditures, while also reducing the bureaucratic, cost, and social barriers family caregivers face while trying to access respite. All of the real and potential sources of funding identified in this guide can be perceived as building blocks for Lifespan Respite systems. In time, once Lifespan Respite grants have allowed states to build or enhance these coordinated systems of respite care, Lifespan Respite Care Programs will increasingly become a source of service delivery dollars, especially for the countless number of family caregivers who currently are not eligible for any existing source of federal or state funding for respite. While Lifespan Respite Care Programs are intended to maximize and more efficiently use existing funding sources, given current fiscal challenges, the success of the program is dependent on increased state and federal investments in the Lifespan Respite Care Program as well.

This guide outlines the major sources of federal funding that states are using or could potentially use for some aspect of respite service improvement or delivery through their Lifespan Respite systems. It is intended to help family caregivers as respite consumers and respite providers obtain federal funds for which they qualify, help state government and state Lifespan Respite grantees and partners become more knowledgeable about securing respite funds and maximizing their use, and help state and federal policymakers become more aware of the importance and interconnectedness of these funding sources. The Lifespan Respite Care Program is described in the text box below. It is presented here to emphasize the overarching systems-building role that Lifespan Respite Care Programs are intended to have and to illustrate that the goal of Lifespan Respite Care Programs is to use the federal programs described in this guide as the building blocks for statewide coordinated systems for respite services, programs, and resources.

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Lifespan Respite Care Program

**Authorizing legislation:**
Lifespan Respite Care Act of 2006, Title XXIX of the Public Health Service Act, P.L. 109-442.

**Currently authorized through:**
September 30, 2011. Appropriations have continued annually past this date.

**Program purpose:**
To expand and enhance respite care services; to improve statewide dissemination and coordination of respite care; and to provide, supplement, or improve access to and quality of respite care services.

**Funding:**
Competitive grants are awarded to states that show the greatest likelihood of implementing or enhancing their Lifespan Respite systems statewide. State governors designate a lead agency to receive the funding. That entity must involve an Aging and Disability Resource Center and work in collaboration with a State Respite Coalition or organization. Recipients may subcontract with public or private entities to carry out the mandatory and optional activities described below in Activities supported by the funding. States must provide a 25% match, which may be cash or in-kind.

**Activities supported by the funding:**
Funds must be used for

- developing or enhancing lifespan respite programs at the state and local levels,
- providing respite care services for family caregivers who care for children or adults,
- recruiting and training respite workers and volunteers,
- providing information to caregivers about available respite services, and
- assisting caregivers in gaining access to such services.

**Respite connection:**
Respite is the primary activity to be undertaken under this funding authority. By building or enhancing Lifespan Respite Care Programs, defined as “coordinated systems of community-based respite for family caregivers of adults or children with special needs,” family caregivers are provided with improved access to quality respite services.

**Issues for consumers, providers, and advocates:**
Each Governor submits an application with descriptions of the eligible state agency; family caregivers to be served and eligibility criteria; existing respite services; methods for coordinating respite services and information; training programs; plans for administration, collaboration, and coordination with other related services; how family caregivers and others will participate in planning and implementation; how other federal, state, and local funds, programs, and other resources will be maximized; unmet needs; quality and safety monitoring procedures; expected results; and evaluation plans.

The first Lifespan Respite grants were awarded in 2009 to 11 states and the District of Columbia: Alabama, Arizona, Connecticut, District of Columbia, Illinois, Nevada, New Hampshire, North
Carolina, Rhode Island, South Carolina, Tennessee, and Texas. An additional 12 states were funded in 2010: Delaware, Kansas, Louisiana, Massachusetts, Minnesota, Nebraska, New York, Oklahoma, Pennsylvania, Utah, Washington, and Wisconsin. In 2011, the following states received Lifespan Respite grants: Colorado, Hawaii, Montana, New Jersey, Ohio, and Virginia. In 2012, seven of the original 2009 states received new grants to build upon and expand efforts begun during their previous three years of work. These grants required states to provide gap-filling respite services to family caregivers and work with the Administration for Community Living (ACL) to develop program performance and outcome measures. In 2013 and 14, additional states received these Integration and Sustainability grants to complete the work they had begun. New states, Arkansas and Florida, were awarded Lifespan Respite grants in 2014 and 2015 respectively. As of 2015, a total of 33 states and DC had been awarded initial implementation grants.

Federal funding agency:  
U.S. Department of Health and Human Services, Administration for Community Living (ACL), Center for Integrated Programs (CIP), Office of Consumer Access and Self Determination

Eligible entity:  
State agency administering the Older Americans Act, the state’s Medicaid program, or another agency designated by the governor.

Points of contact:  
Contact information and project updates for the Lifespan Respite Care Program grantees can be found on the ARCH National Respite Network and Resource Center website.  
http://www.archrespite.org/lifespan-programs

Related links:  
Catalog of Federal Domestic Assistance: Lifespan Respite Care Program.  
https://www.cfda.gov/index?s=program&mode=form&tab=core&id=3a56cd68b41063d2050ab1d50a55259a


Administration for Community Living, Administration on Aging, Office of Integrated Programs.  
Lifespan Respite Care.  http://acl.gov/Programs/CIP/OCASD/LifespanRespite

References:  
http://www.arch.memberlodge.org/2014ConfProgram#LifespanPanel

U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging (2014). *The Lifespan Respite Care Program*. Washington, DC.  

http://acl.gov/About_ACL/Budget/docs/FY_2016_ACL_CJ.pdf
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