



The Lifespan Respite Care Program

BACKGROUND

Who are caregivers?

Caregivers have often been called the backbone of America's long-term care system. On a daily basis, family caregivers assist relatives and loved ones of all ages with routine daily tasks like bathing and homemaking to carrying out more complex health-related interventions like medication administration and wound care and managing the complex needs of children and adults with disabilities. In 2009, it was estimated that 29% of the population, or nearly 67.5 million people, provided some type of care to children and adults of any age, including the elderly, with special needs. These caregivers provided nearly 20 hours of care per week and often do so at the risk of great physical, emotional, and financial hardship.¹

What is respite?

Respite is a key component of family support and home and community-based long-term services and supports. Respite services strengthen family systems while protecting the health and well being of both caregivers and care recipients. The Lifespan Respite Care Act of 2006 defines *respite care* as "planned or emergency care

provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that child or adult." Respite services may be provided in a variety of settings, including the home, adult day care centers, or residential care facilities.

ABOUT THE LIFESPAN RESPITE CARE PROGRAM

State legislated Lifespan Respite Programs have been in existence since 1997 when Oregon became the first state to create such a program. Since that time, other states have developed Lifespan Respite Programs reflecting the unique and diverse needs of their caregivers and care recipients. Despite the varied approaches to designing and administering these early Lifespan Respite Care Programs, the unifying characteristic of each is a coordinated approach to ensuring respite services are available to all who need them.

The Federal Lifespan Respite Care Act was authorized by Congress in 2006. Since 2009, the U.S. Administration on Aging (AoA) has been implementing the program. AoA is working closely with representatives from across the age and disability spectrum to ensure that Lifespan Respite Care Programs meet the respite needs of caregivers of children and adults of all ages with special needs.

¹ Source: Caregiving in the U.S.: 2009. National Alliance for Caregiving/AARP, November 2009. <http://www.caregiving.org/>

FACTS

AOA'S VISION FOR LIFESPAN RESPITE CARE PROGRAMS

Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. Such programs reduce duplication of effort and assist in the development of respite care infrastructures at the state and local levels. Once implemented, Lifespan Respite Care programs will improve the delivery and quality of respite services available to families across age and disability spectrums by establishing coordinated lifespan respite systems.

Lifespan Respite Care Programs advance the following objectives:

1. Expand and enhance respite services in the states;
2. Improve coordination and dissemination of respite services;
3. Streamline access to programs;
4. Fill gaps in service where necessary; and
5. Improve the overall quality of the respite services currently available

LIFESPAN RESPITE CARE PROGRAM GRANTEES

Since 2009, Congress has appropriated nearly \$2.5 million per year to implement Lifespan Respite Programs. As of 2011, competitive grants of up to \$200,000 each were awarded to a total of thirty eligible state agencies.

The 2009 grantees are Alabama, Arizona, Connecticut, District of Columbia, Illinois, Nevada, New Hampshire, North Carolina,

Rhode Island, South Carolina, Tennessee and Texas.

The 2010 grantees are Delaware, Kansas, Louisiana, Massachusetts, Minnesota, Nebraska, New York, Oklahoma, Pennsylvania, Utah, Washington State, and Wisconsin.

In 2011 Colorado, Hawaii, Montana, New Jersey, Ohio and Virginia received grants to begin implementing Lifespan Respite Care Programs. Additionally, the District of Columbia, Delaware, Nevada, North Carolina, Rhode Island, South Carolina, Tennessee and Texas received Program Expansion Supplement Grants to focus on the provision of respite care services and expand program development activities.

Eligible state agencies administer the State's program under the Older Americans Act of 1965; the State's program under title XIX of the Social Security Act; or are designated by the Governor to administer the State's program under this title. The eligible state agency must be an Aging and Disability Resource Center and work in collaboration with a public or private non-profit statewide respite care coalition or organization.

ADDITIONAL INFORMATION

For additional information about the Lifespan Respite Care Program, including specific details about each of the grantees, please visit the AoA web site at: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx

In 2009, AoA funded the Family Caregiver Alliance (FCA) in San Francisco, CA with a sub-contract to the ARCH National Respite

FOR MORE INFORMATION ABOUT AOA

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Network to provide Technical Assistance to Family Caregiver and Lifespan Respite Programs. Together, FCA and ARCH are translating best practices for caregiver services and supports into practical tools and resources needed by program administrators and front-line staff of Family Caregiver and Lifespan Respite Care Programs. For more information, please visit the Family Caregiver Alliance and ARCH National Respite Network web sites at:

Family Caregiver Alliance:

http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2343

ARCH National Respite Network:

<http://chtop.org/ARCH/Lifespan-T/TA.html>

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