



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

WHAT ARE 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 IMPLEMENTATION

Since 2009, Congress has appropriated approximately \$2.5 million per year to implement Lifespan Respite Programs. As of 2012, competitive grants of up to \$200,000 each were awarded to eligible agencies in thirty states and the District of Columbia.

Eligible state agencies are those administering the State's program under the

Older Americans Act of 1965; the State's program under title XIX of the Social Security Act (Medicaid); 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.

With these initial three-year grants, states have developed or built upon respite infrastructures through a variety of approaches designed to enhance or improve access to and receipt of respite services.

Examples of grantee activities include:

- Environmental scans to better understand available respite programs and family caregiver needs;
- Marketing and outreach campaigns to better educate family caregivers about respite and how to access services;
- Training of volunteer and paid respite providers to increase the availability of respite services;
- Partnering with communities of faith to develop respite programs;
- Developing or enhancing statewide databases of respite care programs, services and information to improve access for family caregivers; and
- The development and implementation of person centered respite service options such as vouchers.

In 2012, AoA funded seven of the original 2009 states with new grants to build upon and expand the efforts begun during their previous three years of work. Grantees are focusing on more fully integrating Lifespan Respite Care Programs into the state's systems of long-term services and supports.

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These new grants also require states to provide gap-filling respite services to family caregivers and work with AoA to develop program performance and outcome measures.

TECHNICAL ASSISTANCE

Technical assistance is a key component of effective program development. Since program implementation began in 2009, AoA has funded the ARCH National Respite Network and Resource Center to provide technical assistance to the Lifespan Respite Program grantees and the field.

ARCH's current technical assistance activities focus on assisting states in the development of sustainable, integrated and high-quality respite programs across the lifespan; supporting the development of a framework to measure program performance and outcomes; and collecting, synthesizing, disseminating and stimulating research in the field of respite and family caregiver support.

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

ARCH National Respite Network:

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

FOR MORE INFORMATION ABOUT AOA

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ADMINISTRATION ON AGING, WASHINGTON DC 20201

PHONE: 202.619.0724 | FAX: 202.357.3555 | EMAIL: AOAINFO@AOA.GOV | WEB: [HTTP://WWW.AOA.GOV](http://WWW.AOA.GOV)

FACEBOOK: [HTTP://WWW.FACEBOOK.COM/AOA.GOV](http://WWW.FACEBOOK.COM/AOA.GOV)

