



The Lifespan Respite Care Program

BACKGROUND

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.

THE LIFESPAN RESPITE CARE PROGRAM: HISTORY AND OVERVIEW

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.

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 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 to \$4 million per year to implement Lifespan Respite Programs. As of 2018, initial grants of up to \$200,000 each have been awarded to eligible agencies in thirty-seven states and the District of Columbia.

Eligible state agencies are those that administer 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 work in collaboration with the Aging and Disability Resource Center and a public or private non-profit statewide respite care coalition or organization. With their initial three-year grants, states developed or enhanced respite infrastructures through a variety of approaches designed to improve access to and receipt of



respite services. Examples of grantee activities and accomplishments 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;
- Mini-grant programs to foster development of local respite options and resources;
- 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.

Many of the states have gone on to receive additional grant funding to build upon and expand the efforts begun during their initial 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. These grants require states to provide gap-filling respite services to family caregivers and to work with ACL to develop program performance and outcome measures.

In its implementation of the program, the Administration for Community Living (ACL) has worked 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.

TECHNICAL ASSISTANCE

Technical assistance is a key component of effective program development. Since 2009, ACL 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 ACL web site at: <https://www.acl.gov/node/441>

ARCH National Respite
Network: <https://archrespite.org>

For more information about ACL

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