What is Lifespan Respite?

The federal Lifespan Respite Care Program, established in 2006, is administered by the Administration for Community Living, U.S. Department of Health and Human Services. Lifespan Respite is defined as “coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs.” To date, 37 states and the District of Columbia have received initial Lifespan Respite grants to build or enhance state Lifespan Respite systems. Many of the grantees have received additional grants from ACL to continue their efforts and to sustain Lifespan Respite grant activities. State grantees are required to use their federal and state matching funds to:

★ develop or enhance lifespan respite programs at the state and local levels;
★ provide planned and emergency respite for family caregivers of children and adults;
★ train and recruit respite workers and volunteers;
★ provide information to caregivers about available respite and support services; and
★ assist caregivers in gaining access to such services.

Which states paved the way for the federal Lifespan Respite Program?

- From 1997 to 2000, three states enacted state legislation to implement Lifespan Respite Programs (Oregon, Nebraska, and Wisconsin). The goals of each were to establish state and local infrastructures for coordinating resources and improving access to respite regardless of age or disability. Oklahoma state agencies voluntarily collaborated to implement a statewide Lifespan Respite Program without state legislation in 2000.

- State legislation to authorize AZ’s Lifespan Respite Program was enacted in 2007. Texas enacted a Lifespan Respite law in June 2009 and began implementation in September 2009.

- Some private, non-profit state respite coalitions, such as those in Delaware, Alabama, and Tennessee, engaged in Lifespan Respite program activities prior to enactment of the federal law by acting as statewide coordinating entities for respite services, offering respite vouchers or providing respite services directly to families, developing online directories of respite services and providers, and/or recruiting and training respite providers and volunteers.
What does a Lifespan Respite program look like and what does it provide?

- Each state lifespan respite grantee adapts to meet individual state needs, but the defining characteristic of each is working to establish a statewide, coordinated approach to ensure access to respite services for any family caregiver in need.

- State Lifespan Respite programs often establish and rely on statewide, community-based or regional networks or coalitions to build and ensure respite capacity. These partnerships may include family caregivers, respite providers, state government agencies, area agencies on aging, non-profit organizations, home health services, local business, faith communities, and volunteers.

- Services typically offered by Lifespan Respite programs are engaging in public awareness, providing information and referral services, building diverse respite partnerships, recruiting paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, training respite providers and caregivers, identifying service gaps and creating new respite resources by building on existing services.

- Some state Lifespan Respite grantees are increasingly supporting direct service delivery by providing Lifespan Respite voucher programs that help family caregivers pay for respite services, awarding mini-grants to community or faith based agencies to provide respite services, or organizing volunteer or faith-based respite services.

History of the Oregon, Nebraska, and Oklahoma Lifespan Respite Models

The Federal Lifespan Respite Care Act, enacted by Congress in 2006 and funded for the first time in 2009, was based on the ground-breaking work of the following three states.

Oregon

The Oregon Lifespan Respite Care Program was the first state Lifespan Respite Program created by state Legislation in 1997 with the passage of House Bill 2013. The state Department of Human Services (DHS) was directed to assist local communities in building respite access networks for family and primary caregivers regardless of age, income, race, ethnicity, special need or situation. DHS, through the Oregon Lifespan Respite Care Program, contracted with private non-profit, for-profit or public agencies in communities throughout the state. Each of these Local Respite Networks (LRNs) acted as a local source of information, referral and access to local respite.

---

1 Despite the fact that the Oregon Lifespan Respite Program was unfunded in 2010 because of serious state budget constraints, the program is included in this fact sheet because it serves as a unique model for Lifespan Respite coordination that successfully demonstrated improved access to respite for over 14 years and represents a best practice.
However, in June 2010, due to state budget cutbacks, the state discontinued its contracts with the 22 Lifespan Respite Networks (LRNs), which up until that time, were providing the following services in all 36 counties: 1) recruitment and training of respite providers; 2) coordinating respite-related services based on each caregiver and family's needs; 3) information and referral to respite-related services; and 4) linking families with potential respite care payment resources. Prior to June 2010, approximately 5000 respite referrals were made for more than 3000 families each year. All age groups were served. Care recipients also represented a wide range of disabilities.

**Nebraska**

The *Nebraska Lifespan Respite Network* was created by state legislation in 1999 and was implemented by the Nebraska Department of Health & Human Services (DHHS). This program consists of the Lifespan Respite Network and the Lifespan Respite Subsidy Program. The purpose of the Lifespan Respite Network is to serve as a statewide system for the coordination of respite resources that serve the lifespan. DHHS has contracts with six local entities, one in each region of the state. The Lifespan Respite Network is responsible for information and referral, respite provider recruitment, marketing activities to increase the public's awareness of respite, connecting caregivers to respite resources, coordinating training opportunities for providers and consumers, and quality assurance and program evaluation. The Lifespan Respite Subsidy is available to persons across the lifespan with special needs not receiving respite services from any other government program. Eligibility is determined based on an individual’s special need and financial guidelines. The Nebraska Lifespan Respite Network has been highlighted as a model for community-based long-term care by the National Conference of State Legislatures. In FY 2010, Nebraska's DHHS, in partnership with the Nebraska Lifespan Respite Network and Answers4Families (ADRC) received an initial three-year federal Lifespan Respite Grant to enhance its existing program. The program received another federal Lifespan Respite grant in FY 2014 to enhance and sustain activities. The Network continues to be supported by state funds.

**Contact:**
Sharon Johnson
Program Coordinator
Division of Children and Family Services
Nebraska Department of Health and Human Services
(531) 220-6077
Email: sharon.j.johnson@nebraska.gov
Website: [https://nrrs.ne.gov/respite/](https://nrrs.ne.gov/respite/)

**Oklahoma**

The *Oklahoma Respite Resource Network* (ORRN), was a statewide partnership of public and private agencies working to support families and caregivers by increasing the availability of respite. From 2000 - 2013, state government agencies, including developmental disabilities,
mental health, aging, maternal and child health and others, came together voluntarily with private agencies and foundations to pool respite resources and disburse them through a single voucher program to help families pay for respite. During this time, the voucher programs was managed by a single state entity, the OK Department of Human Services (DHS). Currently, the Lifespan Respite Voucher program is funded by federal Lifespan Respite Program grant funds, monitored by DHS Aging Services, and operated by the University of Oklahoma Health Sciences Center (OUHSC) Sooner SUCCESS program. Eligible family caregivers must live in families with incomes no higher than $90,000 annually and be caring for someone with a disability or chronic condition between the ages of 0-59. Families are entitled to $400 in vouchers every three months based on availability of funds. Families applying to the state for a respite voucher are considered the employer and are encouraged to use respite providers from their networks of family, friends or co-workers, civic organizations, churches, or other appropriate public or private agencies. The state has also awarded part of their Lifespan Respite grant funds to several nonprofit entities to provide additional respite resources. Other state respite voucher programs include the Developmental Disabilities Services (DDS) Respite Voucher Program and the AAA (Area Agency on Aging) Respite Voucher Program. In 2013, the state received a three year Integration and Sustainability grant from ACL to continue Lifespan Respite activities, and in 2017, received an Advancing State Lifespan Respite Systems grant.

Contact:
Nadine Walter
Lifespan Respite Grant Manager
OK Department of Human Services
Aging Services
50 NE 23rd Street
Oklahoma City, OK 73105
(405) 306-9730
Nadine.Walter@okdhs.org

Prepared by the ARCH National Respite Network and Resource Center. For more information, contact ARCH, 703-256-2084, jkagan@archrespite.org or visit www.archrespite.org.

This project was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.