



Toolkit: Lifespan Respite "101"

Original State Lifespan Respite Programs as Best Practices

What is Lifespan Respite?

The federal Lifespan Respite Care Program, established in 2006, is administered by the Administration for Community Living (ACL), 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." Initial Lifespan Respite grants have been awarded to 37 states and DC to build or enhance state Lifespan Respite systems. Many of the grantees have received additional grants from ACL to help sustain Lifespan Respite grant activities. Grantees are required to use federal and 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, Oregon, Nebraska, and Wisconsin were the first three states to enact state legislation to implement Lifespan Respite Programs. 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. TX enacted a Lifespan Respite law in June 2009.
- Private, non-profit state respite coalitions 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/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 building or enhancing 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 care services, local business, faith communities, and volunteers.
- Services typically offered by Lifespan Respite programs are public awareness activities, information and referral services, recruitment and training of paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, identifying service gaps and creating new respite resources by building on existing services.
- Most Lifespan Respite grantees provide planned and emergency respite care through Lifespan Respite voucher programs that help family caregivers pay for respite services, by awarding mini-grants to community or faith based agencies to provide respite services, or organizing volunteer or faith-based respite opportunities.

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

The Federal Lifespan Respite Care Act was modeled on ground-breaking work in Oregon, Nebraska, Oklahoma and Wisconsin. A short history of these programs follows:

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 2013.¹ The OR 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 OR 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 respite.

However, in June 2010, due to state budget cuts, the state discontinued its contracts with the 22 Lifespan Respite Networks (LRNs). Up until that time, the LRNs were providing the following services in all 36 counties: 1) recruitment and training of respite providers; 2) coordinating respite-related services based on caregiver and family needs; 3) information and referral to respite-related services; and 4) linking families with potential respite care payment resources. Each year until 2010, approximately 5000 respite referrals were made for more than 3000 families. All age groups were served and care recipients represented a wide range of disabilities.

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.

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.

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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 to 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 program was managed by 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.

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Wisconsin

In **Wisconsin**, the 1999 state legislation authorizing the Wisconsin Lifespan Program required that coordinated, non-categorical respite services be available locally to provide reliable respite services when needed by families and caregivers regardless of age, disability, or geographic location. In collaboration with the Department of Health and Family Services, the Respite Care Association of Wisconsin (RCAW), which is a nonprofit private entity, is the state administering body of the Wisconsin Lifespan Respite Program and promotes the state respite agenda. RCAW serves as the central point of contact for respite programs across the state. Programs and activities include recruitment and training of respite care workers; on-line training curriculum for respite care workers; on-line registry of trained respite care workers; and information and referral. RCAW offers mini-grants throughout the state for activities that support their mission, and a respite care reimbursement program for family caregivers. In FY 2010, the Wisconsin Department of Health Services – Division of Long Term Care, in collaboration with the RCAW, Easter Seals Wisconsin, and the Wisconsin Quality Home Care Commission (WQHCC), received a three-year federal grant to enhance the state’s Lifespan Respite Care Program, and in 2013, the state received a follow-on Integration and Sustainability grant.

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