



Fact Sheet: Model State Lifespan Respite Programs

What is Lifespan Respite?

The Lifespan Respite Care Act enacted in 2006 defines lifespan respite as coordinated systems of accessible, community-based respite care services for family caregivers of children and adults with special needs. The law requires state grantees 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 are already on the road to lifespan respite?

- From 1997 to 2000, three states enacted legislation to implement Lifespan Respite Programs (Oregon, Nebraska, Wisconsin), which establish state and local infrastructures for developing, providing, coordinating and improving access for respite to residents of the state regardless of age or disability.
- Oklahoma state agencies voluntarily collaborated to implement a statewide Lifespan Respite Program (see below) without state legislation in 2000.
- Maryland, through state legislation, established a State Coordinating Council for Family Caregiver Support. Part of the Maryland Council's charge is to review successful lifespan respite care programs in other states.
- Texas enacted a Lifespan Respite law in June 2009 and began implementation September 2009. AZ's Lifespan Respite legislation was enacted in 2007. Michigan passed Lifespan Respite legislation in July 2004, but a program was never funded.
- Some state respite coalitions, such as those in Delaware, Alabama, and Tennessee, function as State Lifespan Respite Programs by acting as a statewide coordinating entity for respite services, offering vouchers or providing respite services directly to families who do not qualify for existing respite programs, and/or recruiting and training providers and volunteers.
- On September 24, 2009, twelve states were awarded first-time federal Lifespan Respite grants to build or enhance state Lifespan Respite programs (AL, AZ, CT, DC, IL, NC, NH, NV, RI, SC, TN, and TX). For program abstracts, see <http://chtop.org/ARCH/Lifespan-T/TA.html>

What does a lifespan program look like and what does it provide?

- Each state lifespan respite program has been adapted to meet their individual state needs, but the defining characteristic of each is the statewide, coordinated approach to ensure respite services for those in need. Some of the lifespan respite programs have established community-based networks that rely on the development of local partnerships to build and ensure respite capacity. These local partnerships include family caregivers, providers, state and federally funded programs, area agencies on aging, non-profit organizations, health services, schools, local business, faith communities, and volunteers.
- In all Lifespan states other than Oklahoma, local networks are the central point of contact for families and caregivers seeking respite and related support regardless of age, income, race, ethnicity, special need or situation. Respite stipends may be limited by income eligibility. Providing a single point of contact for families to access respite information and services is crucial to assisting families in helping themselves.
- Services typically offered by Lifespan Respite Programs are provision of public awareness information to the community, building diverse respite partnerships, recruitment and training of paid and volunteer respite providers, connecting and matching families with respite payment resources and providers, coordinating respite related training for providers and caregivers, identifying gaps in services and creating respite resources by building on existing services.

Oregon, Nebraska, Wisconsin, Oklahoma and Arizona Lifespan Respite Programs

- The **Oregon Lifespan Respite Care Program** was created by the Legislature 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, contracts with private non-profit, for-profit or public agencies in communities throughout the state. Each of these agencies acts as a single local source of information, referral and access to local respite. In 2007, Senate Bill 648 approved funding for DHS to renew a strong commitment in ensuring the Community Lifespan Respite Care Program partners are able to coordinate respite for family caregivers. Currently, 22 networks in Oregon provide the following services in all 36 counties:
 - ♦ Recruitment and training of respite care providers.
 - ♦ Coordinating respite-related services based on each caregiver and family's needs.
 - ♦ Information and referral to respite-related services.
 - ♦ Linking families with potential respite care payment resources.

Approximately 5000 respite referrals are made for more than 3000 families each year. Over 3700 individuals receive respite as a result. The population served represents all age groups: adults 18-59 (12%), children 0-12 (30%), adolescents 13-17 (6%), seniors ages 60-75 (17%), and elderly ages 76+ (35%). Care recipients also represented a wide range of disabilities including developmental disabilities (18%), physical disabilities (11%), mental illness, emotional or behavioral conditions (15%), Alzheimer's (14%), chronic

illness (8%), medical fragility (6%), frail elderly (12%), individuals at risk of abuse or neglect (8%), and others or not reported (5%).

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- The **Nebraska Lifespan Respite Care Act** was created by legislation in 1999 and implemented by Nebraska Department of Health & Human Services (DHHS). The Lifespan Respite Care Act established the Nebraska Lifespan Respite Services Program, which consists of the Lifespan Respite Network and the Lifespan Respite Subsidy Program. The purpose of the Lifespan Respite Network is to establish 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 for families needing access to respite, recruitment of respite providers, marketing activities to increase the public's awareness of respite, coordinating training opportunities for providers and consumers, and quality assurance and program evaluation. The Lifespan Respite Subsidy component is available to persons of all ages 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 Program was highlighted as a model for community-based long-term care by the National Conference of State Legislatures.

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- In **Wisconsin**, the legislation authorizing the Wisconsin Lifespan Program requires that coordinated, noncategorical respite services be available locally to provide reliable respite services when needed by families and caregivers regardless of age, disability, or geographic location in Wisconsin. 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. Five regional lifespan networks, one in each of the five Department of Health and Family Services regions have been established to serve nine counties. Respite Care Association of Wisconsin is the only statewide organization dedicated to promoting planned and crisis respite care across the lifespan. RCAW serves as the central point of contact for respite programs across the

state. Products and services include training, technical assistance, information and referral, lending library, and publications.

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- The **Oklahoma Respite Resource Network (ORRN)** is a statewide partnership of public and private agencies whose goal is to support families and caregivers by increasing the availability of respite care. State agencies, including developmental disabilities, mental health, aging, maternal and child health and others, have come together voluntarily with private agencies and foundations to pool resources for respite and disburse them through a voucher program managed by a single state entity. Families applying to the state for a respite voucher (families are entitled to \$200-\$400 in vouchers every three months based on availability of funds) are considered the employer and are encouraged to consider as potential respite providers family, friends or co-workers, civic organizations, local churches, child care centers, or other appropriate public or private agencies. The Oklahoma Respite Resource Network relies on an already existing statewide resource and referral system (OASIS) that functions through an 800 toll-free number to link families to the program, to respite services and to training opportunities if families desire them.

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- The **Arizona Lifespan Respite Program**, enacted into law in 2007, was allocated \$500,000 annually for implementation. The Arizona Dept of Economic Security is the lead state agency. Each local Area Agency on Aging (8) is functioning as the local Lifespan Respite Program. Primary caregivers of individuals who do not currently qualify for other publicly funded respite services are eligible, including family caregivers of: persons who are seriously or terminally ill, who do not currently qualify for hospice care; persons under 60 who have significant functional impairments, but are not eligible for disability services; persons with early cognitive deficit resulting in functional impairment, who have not yet received a “likely” diagnosis of dementia; Grandparents or relative caregivers less than 55 years of age caring for children 18 and younger; and veterans not qualified for respite services from the Veteran’s Administration. Although income is not a disqualifying factor, services will be targeted to those individuals in greatest economic and social need. Because funding is limited and in order to offer respite to the maximum number of caregivers, cost sharing will be required and is based on the care recipient’s household income, beginning at 250% of the Federal Poverty Guidelines. In March 2009, the program experienced a funding cut because of state budget constraints, but will be up and running again with a new federal Lifespan Respite

Grant.

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