Fact Sheet: Model State Lifespan Respite Programs

Which states are already on the road to lifespan respite?

- Three states have implemented Lifespan Respite Programs (Oregon, Nebraska, Wisconsin) through state legislation, 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 also has implemented a statewide Lifespan Respite Program (see below) without state legislation.

- Arizona passed legislation establishing and funding a Lifespan Respite Program in 2007, which is currently in the planning phase. Implementation is expected in 2008.

- Maryland, through state legislation, established a State Coordinating Council for Family Caregiver Support. Part of Maryland’s charge is to review successful lifespan respite care programs in other states.

- Michigan passed Lifespan Respite Legislation in July, 2004, but a program has not yet been funded.

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

- Each 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. Many 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.

- These 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 providing public awareness information to the community and 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 and Oklahoma Lifespan Respite Programs

• Oregon was the first state to implement a Lifespan Respite Program in 1997. The Director of the Oregon Department of Human Services (DHS) is charged by state law to develop and encourage statewide coordination of respite care services. The Department works with community-based nonprofits, businesses, public agencies and citizen groups to identify gaps in services, generate new resources and develop community programs to meet the needs. The Program offers technical assistance, works directly with Lifespan networks, and promotes the state respite agenda. All of Oregon’s 36 counties are currently by 23 regional lifespan respite programs.

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• Modeled on the Oregon Lifespan Respite Program, the Nebraska Respite Network was created by legislation in 1999 and is currently being implemented by Nebraska Health & Human Services System (HHSS). The purpose of the Network is to establish a statewide system for the coordination of respite resources that serve the lifespan. Contracts are in place between HHS and six local entities, one in each region, which are 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. Lifespan Respite Subsidy component of the effort 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 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 (see Promising Practices Issue Brief: Community-based Long-term Care http://www.ncsl.org/programs/health/forum/longtermcare.pdf).

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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), the state administering body of the Wisconsin Lifespan Respite Program provides administrative oversight to the lifespan grantees, offers technical assistance around program and workforce specific issues, 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. Each network is required to provide direct stipends to families. In the last fiscal year, the networks provided a total of 12,463 hours of respite, including over 2500 volunteer hours, to 414 families.

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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 $400 in vouchers for 3 months) 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) to link families to the program, to respite services and to training opportunities.

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