
Lifespan Respite Care: What's Next?

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Family Caregiving in the US

- 50 million family caregivers provide 80% of long-term care in the US.
- Valued at over \$300 billion a year in uncompensated care
- But they cannot do it alone!

Lifespan Respite



- ***Definition:*** Coordinated systems of accessible, community-based respite services for all family caregivers regardless of age or special need.
- **Statewide Programs in OR, WI, NE, OK**
- **MI passed new law in July 04; AZ passed a bill this year with funding**

Characteristics of State Lifespan Respite Programs

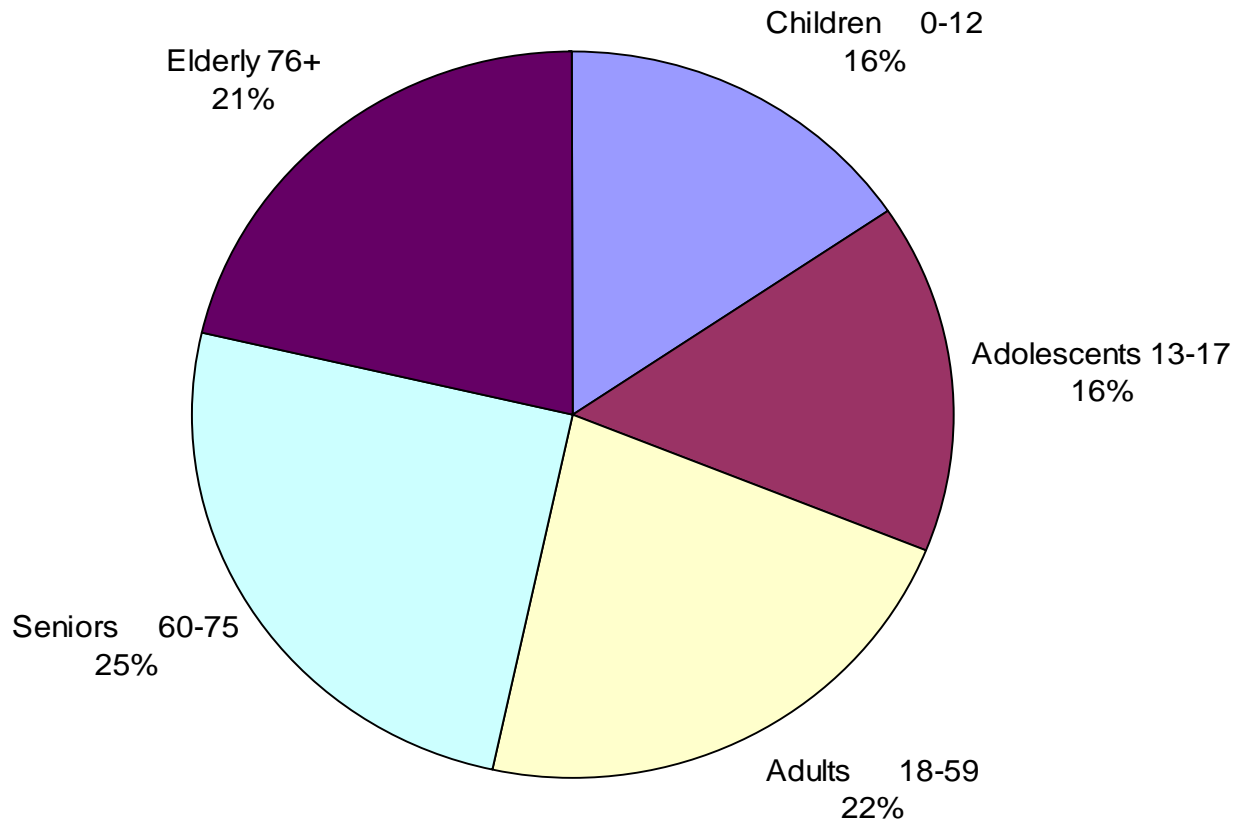
- **Identify and coordinate existing respite resources;**
- **Identify service gaps and create and monitor new respite services;**
- **Recruit, train, and pool paid and volunteer respite providers;**
- **Provide public awareness information; and**
- **Connect families with respite payment resources, providers, and training to promote consumer direction.**

Oregon's Lifespan Program

- In 1997, Oregon Department of Human Services (DHS) charged by state law to develop statewide respite coordination.
- Works directly with 23 local networks serving all 36 counties.
- Categories of Need Served: DD, Physical Disability, Mental Illness, Emotional/Behavioral, Alzheimer's, Chronic Illness, Medical and Elder Fragility, Risk of Abuse and Neglect
- Serve families who qualify for Medicaid, Oregon's Health Care, SSI, DD Self-Directed, DD Family Support (0-17), Family Caregiver Support (OAA), Safety Net SCF, Mental Health, Head Start and Hospice

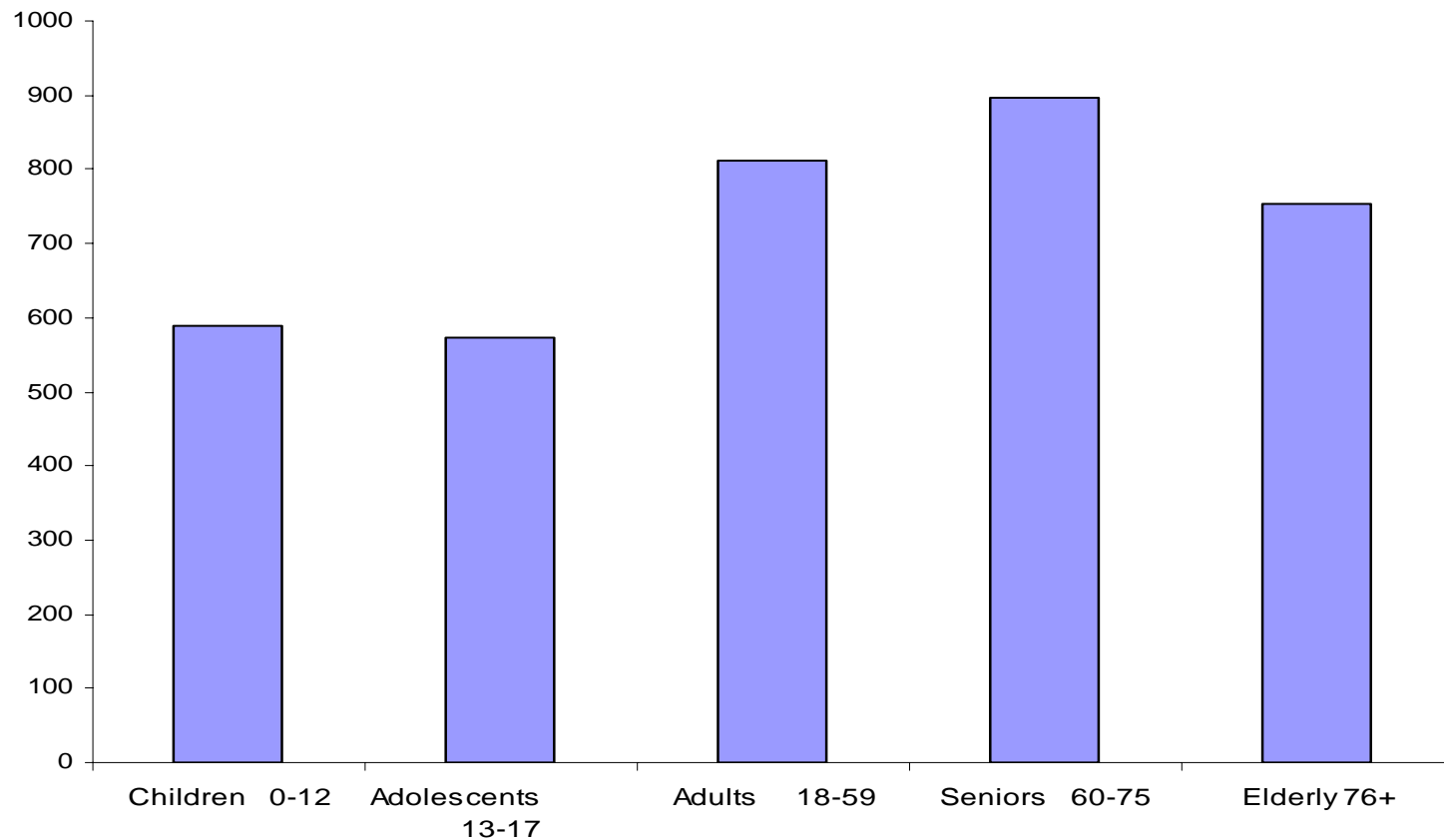
Oregon: Clients Served By Age

Oregon Lifespan Respite - State-wide Clients Served by Age
FY 2005/2006



Oregon: Providers Willing to Serve Target Age Groups

Number of Repite Providers willing to Serve Target Age Groups (this includes all counties)



Nebraska's Lifespan Program

- Modeled on Oregon Lifespan Respite Program, the *Nebraska* Respite Network was created by legislation in 1999
- Implemented by Nebraska Health & Human Services System (HHSS), which contracts with six regional entities. Responsible for:
 - Information and referral
 - Recruitment of providers
 - Public awareness
 - Coordinating training of providers and consumer
 - Quality assurance and program evaluation
 - Lifespan Respite Subsidy program

Oklahoma's Lifespan Program

- ***Oklahoma Respite Resource Network (ORRN)*** is a statewide partnership of public and private agencies
- Partnering State Agencies include: developmental disabilities, mental health, aging, maternal and child health and others
- A voucher program is managed by a single state entity, the Dept of Human Resources.
- Families entitled to \$400 in vouchers for 3 months and are considered the employer.
- Encouraged to consider family, friends or coworkers, civic organizations, churches, child care centers, or other appropriate public/private agencies as respite providers.
- No local entities. ORRN relies on an already existing statewide resource and referral system (OASIS) to link families to the program, to respite services and to training opportunities.

Wisconsin's Lifespan Program

- State Dept of Health and Family Services contracts with Respite Care Association of WI to run the program
- Five regional lifespan networks (one in each of the five Department of Health and Family Services regions) serve seven counties.
- Each network is required to provide direct stipends to families.
- Aging population is not served and program is not statewide because of fiscal constraints.

The Lifespan Respite Care Act Signed into law December 21, 2006



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Lifespan Respite Care Act

Provides competitive state grants for these mandatory uses of the funds:

- **Development of State and local Lifespan Respite systems**
- **Development/Support for planned or emergency respite**
- **Training and recruitment of providers/volunteers**
- **Training of caregivers on how to find, use and pay for respite**

Who is eligible for Lifespan Respite?

Family members, foster parents or other adults providing unpaid care to:

- **Adults who require care to meet basic needs, prevent injury from self or others, or avoid placement in an institutional facility**
- **Children who require care beyond that required by children generally to meet basic needs and prevent injury from self or others**

Funding and State Lead Agency

- **Authorization Levels: \$40 million in FY 08 rising to \$95 million in FY 2011**

- **US Dept. of Health and Human Services will provide competitive grants to:**
 - **State agency which administers Older Americans Act or Medicaid or State agency designated by the Governor**

 - **And is an *Aging and Disability Resource Center* working in mandated collaboration with nonprofit State Respite Coalitions or state respite organizations**

CMS and AoA Vision

To have Aging and Disability Resource Centers in every community serving as highly visible and trusted places where people of all incomes and ages can turn for information on the full range of long term support options and a single point of entry for access to public long term support programs and benefits.

Timeline

- **2007: Secure Congressional Funding**
- **Early 2008: Federal Lead Agency Prepares/Issues Program Guidance (RFP)**
- **Summer 2008: States Apply for Funding**
- **Fall 2008: States Selected and Funds Awarded**
- **October 1, 2008: States Begin to Implement Programs**

Current Status

- **New law cannot be implemented in states unless Congress appropriates the funding for FY08**
- **The FY08 Labor/HHS/Education compromise funding bill passed by House and Senate included \$2 million for Lifespan Respite**
- **President vetoed the bill and the House failed to override.**

State Role: Getting Ready to Implement Lifespan Respite



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Mandated Collaboration: What does it Mean for Your State?

- The State's Application must include:
 - Memorandum of agreement regarding the **Joint responsibility** for the eligible State agency's Lifespan Respite program between the eligible State agency and a public or private nonprofit statewide respite coalition or organization.

Build/Strengthen Local Coalitions

- ARCH Respite Network has about 20 active state respite coalitions and many state points of contact.
- Assess your ability to build a coalition or join a coalition and put a plan in place.

Prepare for State Implementation

- Decide how involved your coalition wants to be in implementation of the Lifespan Respite Care Act
- Develop relationship and build collaborations with ADRCs in the State
- Develop relationships in the Governor's office to assure state lead agency

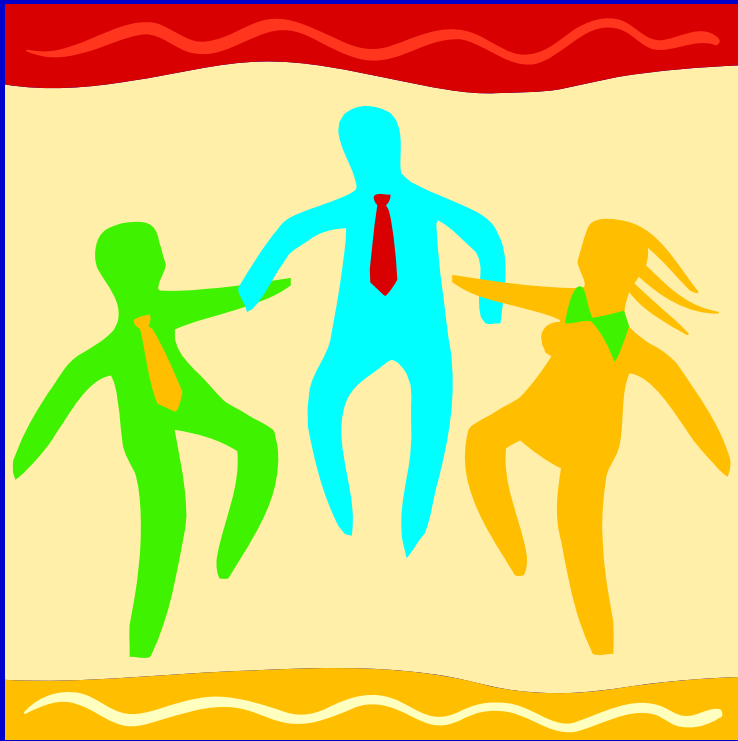
Application Requires:

■ Descriptions of:

- ❖ Who are the family caregivers, how many are there, and what is the extent of their respite needs
- ❖ Existing respite services and unmet need
- ❖ Existing system of respite coordination and extent of unmet need
- ❖ Plan for respite information dissemination and coordination, respite services, worker/volunteer recruitment and training, family caregiver training, and how access will be improved for families
- ❖ Plan for administration, collaboration and coordination of proposed respite activities with other related services
- ❖ How respite system will make maximum use of other Federal, State and local funds, programs, and all other resources
- ❖ How family caregivers and consumers will participate in planning and implementation
- ❖ How quality and safety of respite will be monitored
- ❖ Results expected and planned evaluation procedures

Questions to Consider

- 1. Who else needs to be part of the State Respite Coalition to ensure all family caregivers are served, regardless of age or disability?**
- 2. What do you think your state Lifespan Respite System should look like and what should it provide?**
- 3. Are there any application requirements that your coalition could help fulfill?**



How Can We Help Nationally?

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Lifespan Respite Care Act

Next Steps

- **Thank Cosponsors for leadership and urge them to secure funding for FY08**
- **Urge House and Senate negotiators to retain funding for Lifespan Respite in any new FY08 Labor, HHS, Education Appropriations Bill!!!**

ARCH National Respite Locator

- ARCH Respite Network maintains interactive web listing of respite programs by state.

- **ARCH website:**

<http://www.respitelocator.org>

More Information

- **Join the ARCH National Respite Network**

- **NRC website:**

<http://www.archrespite.org/nrc.htm>