

Lifespan Respite: Who, What, Why, Where and How?

Caregiving in the U.S.

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- More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition.
- 80% of those needing long term services and supports in the U.S. are living at home.



Sources: 1) *Caregiving in the U.S. 2015*. Bethesda, MD: National Alliance for Caregiving and AARP Public Policy Institute.
2) *Rising Demand for Long-Term Services and Supports for Elderly People*, CBO, June 2013

Value of Caregiving

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- The estimated economic value of their unpaid contributions is approximately \$470 billion annually. (*AARP Public Policy Institute, 2015*)
- Informal caregiving in the U.S. by friends and relatives of the aging is valued at \$522 billion a year. (*Rand Corporation, 2014*)

Caregiving is across the Lifespan

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A majority of family caregivers care for someone between 18 - 75 years of age (53%).

- 39% of family caregivers care for someone aged 50 - 74.
- 14% care for someone aged 18 – 49.
- An additional 14.6 million children under 18 years of age have complex service needs.

Source: *Caregiving in the U.S. 2015*. Bethesda, MD: National Alliance for Caregiving and AARP Public Policy Institute and US Health Resources and Services Administration, *National Child Health Survey, 2016*

Caregiving in South Dakota

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- In 2013, more than 84,600 caregivers provided 79 million hours of care.
- The value of their caregiving is estimated at almost \$1,030 million annually.
- They cannot do it alone!

Source: Susan C. Reinhard, Lynn Friss Feinberg, Rita Choula, and Ari Houser. (2015). *Valuing the Invaluable: 2015 Update - Undeniable Progress, but Big Gaps Remain*. Washington, DC: AARP Public Policy Institute

Effects of Caregiving

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- Many derive spiritual, emotional and even physical benefits. For others – high stress leads to poor physical/emotional outcomes. *(Population Reference Bureau, 2016).*
- 4 in 10 caregivers consider their caregiving situation to be highly stressful. *(2015 Caregiving in the US, NAC/AARP)*
- Family caregivers providing substantial assistance with health care experience significant emotional difficulty and role-related effects. *(Wolff, 2016)*

Respite is...

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Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.



Lifespan Respite Care Act definition

PL 109-442

Benefits of Respite

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- Improves caregiver stress levels, which can enhance physical and emotional health and quality of life;
- Improves overall family well-being, family relationships and stability;
- Reduces hospital costs and helps avoid or delay more costly foster care, nursing home or other out-of-home placements.
- Gives care recipient a break too!

Respite: too little, too late

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- 85% of family caregivers do not receive respite. *(2015 Caregiving in the US, NAC/AARP)*
- Of those who do, they often receive too little, too late.



Barriers to Respite



Barriers to Respite

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- Lack of qualified respite providers
- Reluctance to use respite or self-identify as caregiver
- Rural nature of the state
- Access issues
 - ❖ Lack of awareness
 - ❖ Multiple funding streams with different eligibility criteria

Bureaucratic Maze of Funding Streams and Services

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- Various Medicaid Waivers
- Veterans Administration Respite
- National Family Caregiver Support Program
- State Respite Programs
- Family Support Programs

What is Lifespan Respite?



Lifespan Respite...not just care or a service, but.....

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Lifespan Respite Definition:

- Coordinated **Systems** of accessible, community-based respite services for all family caregivers regardless of age or special need.



Lifespan Respite is like a Quilt

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- It weaves together extremely important, but fragmented funding streams, different and duplicative programs, to form a seamless system that make barriers invisible to families.



Characteristics of Lifespan Respite Programs

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- Identify and coordinate existing respite resources/funding at state level
- Maximize use of existing resources/leverage new ones
- Identify service gaps to help create and monitor respite services
- Connect families to respite services, providers, and payment resources
- Recruit and train respite providers
- Promote public awareness about respite

Moving from Barriers to Building Blocks

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By coordinating funding and service streams, Lifespan Respite converts barriers to building blocks for accessible respite systems for all.

First State Lifespan Respite Programs

Oregon's Lifespan Program

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- *State Agency:* In 1997, Oregon Department of Human Services charged by state law to develop statewide respite coordination.
- *Relied on Local Systems to Build Resources:* worked directly with 22 local respite networks serving all 36 counties in Oregon.
- Diverse State Advisory Council brought Lifespan perspective.

Nebraska's Lifespan Program

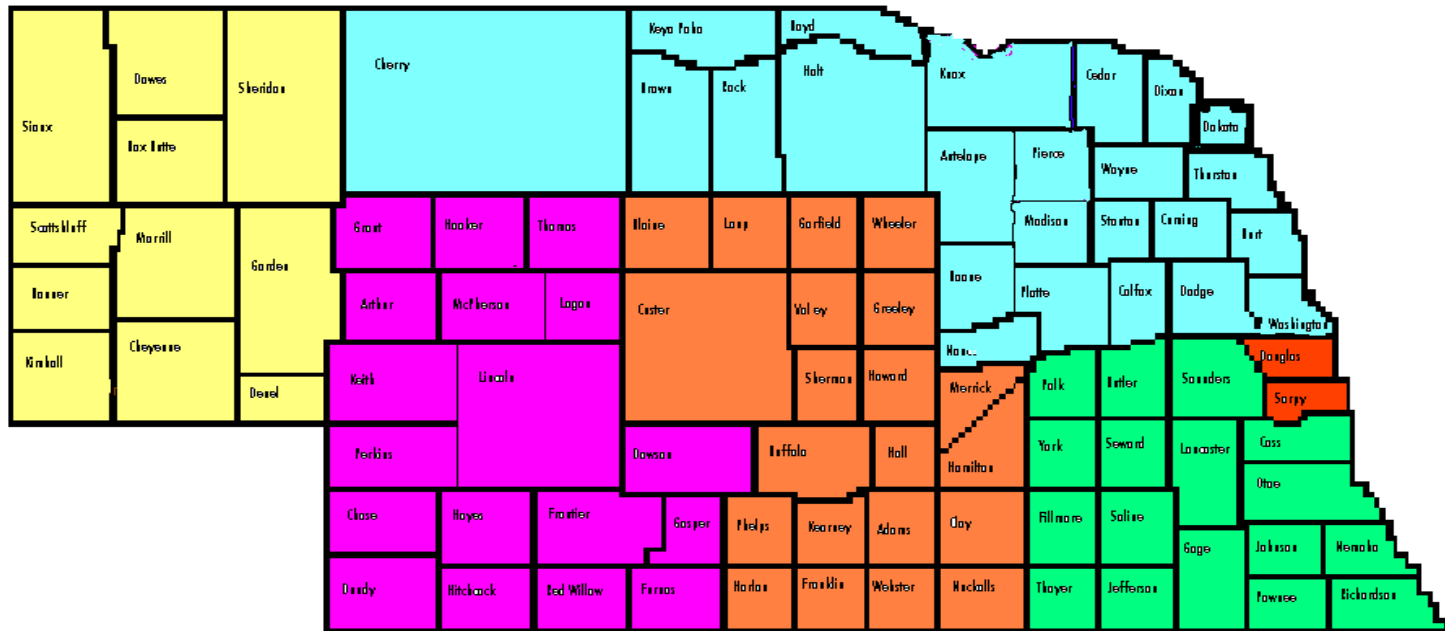
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- *Nebraska* Lifespan Respite Services Program created by legislation in 1999
 - NE Lifespan Respite Network
 - Lifespan Respite Subsidy (payments up to 312% of poverty for families who do not qualify for any existing funding)
- *State Agency*: Implemented by Nebraska Department of Health & Human Services

Nebraska Respite Network

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Regional Structure: HHSS contracts with six (6) regional entities to form the NE Lifespan Network



Oklahoma's Lifespan Program

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- *Oklahoma Respite Resource Network* was a statewide partnership of public and private agencies
- Partnering State Agencies included: developmental disabilities, mental health, aging, maternal and child health and others
- *No local/regional infrastructure*

Oklahoma's Lifespan Program: Consumer-Directed

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- Caregivers eligible for respite vouchers of \$200 - 400 every three months as long as funds are available.
- Encouraged to choose own providers from community/family support network.
- Program relies on existing funding streams.

Federal Lifespan Respite Program



Moving to National Scale

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- Lifespan Respite law signed in 2006
- Funded for the first time in 2009 at about \$2.5 million
- Level funded each year
- In 2016, program received first increase to just under \$3.5 million.



Federal Lifespan Respite Care Program

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Administration for Community Living administers competitive state grants for mandatory use of funds:

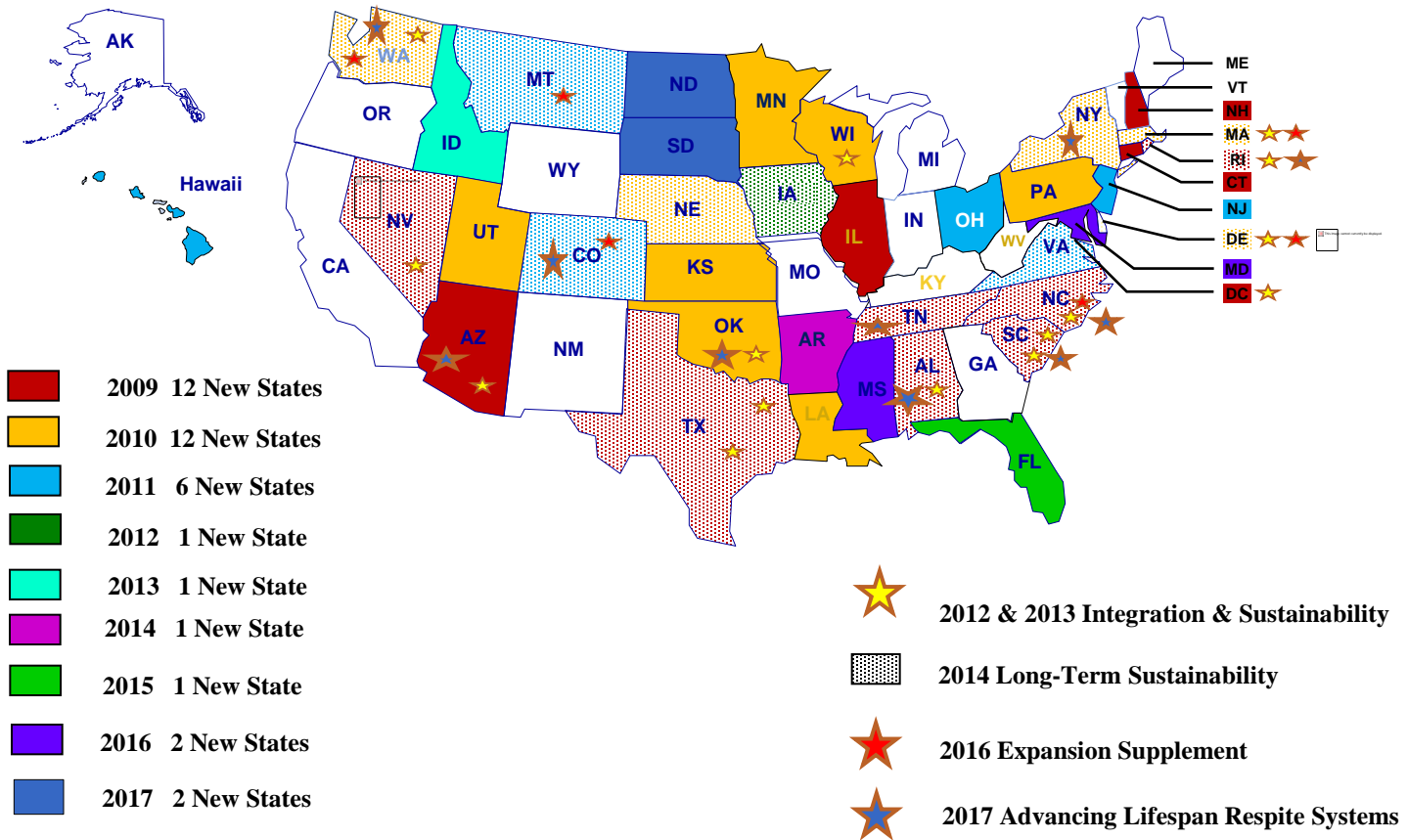
- Development or enhancement of State and local Lifespan Respite systems
- Planned or emergency respite for all ages
- Training and recruitment of providers/volunteers
- Provision of information to caregivers about respite services and assistance in gaining access

Current Status

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**37 States and DC
have received
Lifespan Respite
Grants**

Lifespan Respite States



Courtesy of Administration For Community Living

State Lead Agency

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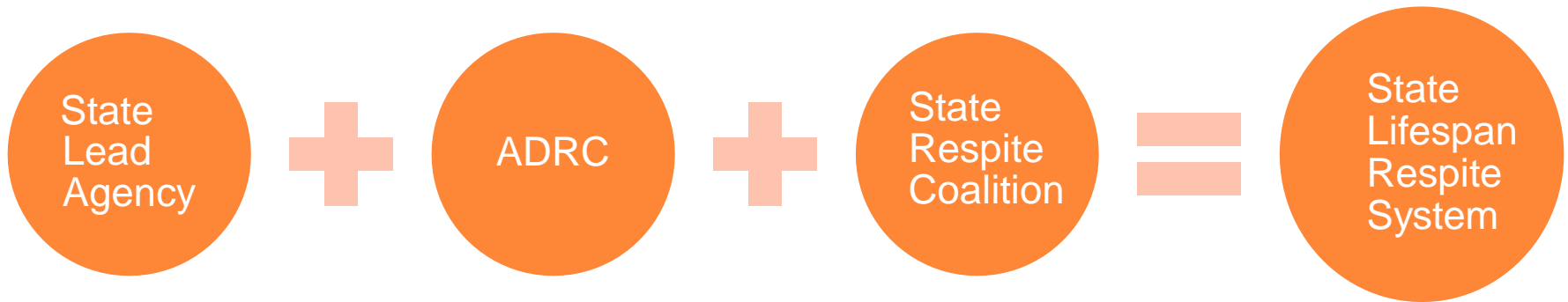
- Eligible State Lead Entities
 - State Units on Aging
 - State Medicaid Agencies
 - Other State Agencies

In concert with...

- Aging and Disability Resource Centers
- State Lifespan Respite Coalition

Lifespan Respite Built on Collaboration

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Mandated Collaboration: What does it Mean?

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- ADRC and State Respite Coalitions must be a partner in program implementation.
- 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.*

Role of State Agency

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- Program Administration and Implementation
- Program Oversight
- Provide a 25% non-federal match

Role of Aging and Disability Resource Center

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- Information and referral
- Gather data
- Engage in outreach, public awareness and information dissemination

Role of State Respite Coalition

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- Many state Respite Coalitions predate Lifespan Respite.
- Coalitions have a history of advocacy and networking; some progressed to service delivery and training.
- Coalition's role and responsibilities determined by decisions made jointly between state agency and the coalition.

Coalition's Significance in Lifespan Respite Program

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- Brings age and disability diversity
- Brings caregiving and respite expertise and skills
- Ensures ongoing support, cohesion, and sustainability for the program

Lifespan Respite Programs Must...

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- Advance State's ability to meet respite needs
- Serve all population/disability groups, especially gap populations
- Coordinate with, and on behalf of, existing respite programs and infrastructures
- Have a consumer focus
- Demonstrate stakeholder collaboration

Questions to Consider



How do we build or strengthen our State Respite Coalition? What role will it play?

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- Advocacy/Program Sustainability
- Conduct Program Oversight
- Provide Guidance and Expertise
- Respite Provider Recruitment/Training
- Develop Products
- Promote Access to Services
- Facilitate Networking

What are the short and long term goals we need to reach to become a Lifespan Respite state?

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- Develop and enhance collaboration between ADRC, Respite Coalition, Governor's office, Legislature, state and local agencies
- Research and identify current state respite needs, strengths, barriers, funding
- Collaborate to design state program –
What should it look like?
How will we measure success?
- Develop sustainability plan

ARCH Resources and Tools

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- ❑ Fact Sheets, Guidebooks and Manuals
- ❑ Webinars
- ❑ Conference Calls
- ❑ Phone/Email Technical Assistance
- ❑ Lifespan Respite Exchange
- ❑ ARCH Quick News Updates
- ❑ National Respite Locator Service

For More Information

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ARCH National Respite Network and Resource Center
<http://www.archrespite.org/>

Lifespan Respite Technical Assistance Center

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