

ENGAGING LIFESPAN RESPITE SYSTEMS TO ENHANCE PROTECTIVE FACTORS

Network for Action
Grantee Meeting



April 24, 2013

Presenter

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Presentation Overview

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- Who are we talking about serving?
- How does respite enhance protective factors?
- What are barriers to respite?
- What is Lifespan Respite?
- How can you get involved?

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Children with Disabilities

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- An estimated 4 to 19% of U.S. children have a chronic physical, developmental, behavioral or emotional condition. (*Health Resources and Services Administration (HRSA), 2011*).



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Importance of Abuse and Neglect Prevention for this Population

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- In 2011, 44 states reported that 11.2% (58,548) of children who were reported as victims of child maltreatment had a disability (*U.S. DHHS, 2012*).
- Children with disabilities almost 4 times more likely to be victims of neglect, physical or emotional abuse, and 3 times more likely to be sexually assaulted than children without disabilities (*Sullivan and Knutson, 2000*).

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Others At-Risk

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- ❑ Children experiencing domestic violence or other family crises
- ❑ Children in kinship families
- ❑ Parents with disabilities

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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

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Benefits of Respite

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- ❑ Improves family caregiver stress levels, which can affect physical and emotional health;
- ❑ Affects overall family well-being and stability by improving marriages, sibling and other family relationships; and
- ❑ Reduces hospital costs and helps avoid or delay more costly foster care or other out-of-home placements.

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Respite Enhances Protective Factors

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- ☐ **Parental Resilience**
- ☐ **Social Connections**
- ☐ **Concrete Supports in Times of Need**

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Respite: Too Little, Too Late

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- ❑ 81% of families of children with disabilities do not receive respite.
- ❑ Of those who do, they receive too little, too late.
- ❑ Respite needs to be meaningful for the child as well as for the caregiver.



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Respite Challenges

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- ❑ Affordability issues
- ❑ Limited qualified providers
- ❑ Reluctance to ask for help
- ❑ Bureaucratic maze of funding streams and services

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What is Lifespan Respite?

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Lifespan Respite

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Definition:

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

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Federal Lifespan Respite Program

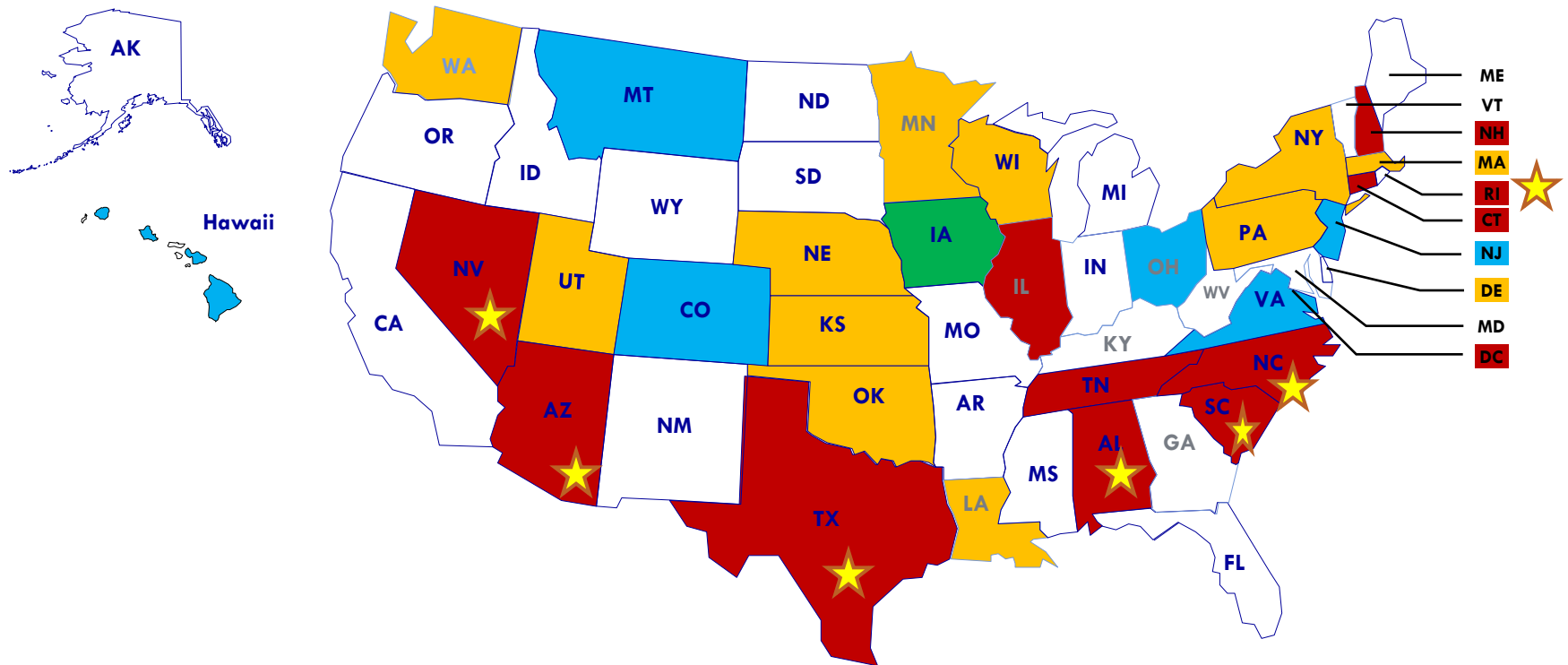
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- Administered by US Administration for Community Living/Administration on Aging
- \$2.5 million each year since FY 2009
- Competitive grants to states

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Lifespan Respite States

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- 2009 Lifespan Respite States (★ = 2012 Integration Grants)
- 2010 Lifespan Respite States
- 2011 Lifespan Respite States
- 2012 Lifespan Respite States

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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

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Mandatory Uses of Funds

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

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Lifespan Respite Grantee Activities

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- Strengthening coalitions and defining stakeholder roles
- Public awareness campaigns
- Partnerships with faith and volunteer communities
- Provider training and recruitment
- Providing planned and crisis respite

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Get Involved

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- ❑ Consider funding respite and crisis nursery services as part of your continuum of prevention services
- ❑ Contact the Lifespan Respite State Lead Agency
- ❑ Become involved in the State Respite Coalition
- ❑ Offer expertise and resources
- ❑ Contact ARCH if your state does not have a Lifespan Respite Program or a State Respite Coalition

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For More Information

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ARCH National Respite Network and Resource Center

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

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