The Power and Possibility of PASRR Webinar Series

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*Please note that you **must** attend the entirety (90 minutes) of this webinar if you wish to receive Continuing Education credits.*

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Best Practices in Lifespan Respite Systems: Lessons Learned from States and Future Directions

PASRR Webinar
December 9, 2014

Today's Webinar

- Overview of Family Caregiving in the US
- Benefits of and barriers to respite
- The federal Lifespan Respite Care Program
- Successful state collaborations
- ARCH Resources

Family Caregiving in the US

- Four in ten adults in the U.S. are caring for an adult or child with significant health issues, up from 30% in 2010.

Source: PEW Research Center, June 20, 2013

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Family Caregiving is Lifespan!

Majority of family caregivers caring for someone under age 75 (56%).

- 28% of family caregivers care for someone age 50-75.
- 28% care for someone under age 50, including children.

Source: Caregiving in the U.S. 2009. Bethesda, MD: National Alliance for Caregiving and Washington, D.C.: AARP, 2009.

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Family Caregivers are the Backbone of US LTSS System

- 80% of those needing long-term services and supports in the US are living at home.
- More than 3.5 million people with intellectual and developmental disabilities (I/DD) live with family caregivers.
- One-third to two thirds of those with long-term mental disorders live with family members.
- Close to 1 million adults with co-existing developmental and intellectual disabilities and mental illness in the U.S. live with their families

Value of Family Caregiving

- Family caregiving valued at over $450 billion a year in uncompensated care, more than total Medicaid spending in 2009.

Caregivers of Individuals with I/DD

- 58% of parents/caregivers spend 40+ hours/week providing support, including 40% spending 80+ hours/week.
- Nearly half (46%) report more caregiving responsibilities than they can handle alone.
- 1 out of 5 families (20%) report that a family member quit their job to stay home.

Source: The Arc. (2011). Still in the Shadows with Their Future Uncertain: A Report on Family and Individual Needs for Disability Supports (FINDS 2011). http://www.thearc.org/document.doc?id=3140

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Caregivers of Individuals with Mental Health Conditions

- Caregivers may be more isolated due to stigma associated with mental illness.
- Caregiving stress can lead to missed work, strained relationships, and physical and mental exhaustion (*National Institute of Mental Health, 2009*).
- When caregiver is under stress, the consumer has greater difficulty following treatment plan (*Perlick, et al., 2004*).

Respite is…

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

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

Respite Helps Prevent or Delay Institutionalization

- The decline of family caregiver health is one of the major risk factors for institutionalization of a care recipient *(Elliott & Pezent, 2008).* Higher caregiver stress among those caring for the aging increases the likelihood of nursing home entry (*USDHHS, 2007*).
- For every $1000 spent on respite, the risk of psychiatric hospitalization declined 8% (*Mandell, 2012*).
- As respite use increases, the probability of nursing home placement decreases (*Kosloski & Montgomery,1995*).

Respite: Too Little….

- 89% of family caregivers do not receive respite.
- 75% of 5000 family caregivers of individuals with I/DD surveyed by The Arc said they could not find respite services.
- A DE survey of family caregivers found only 18% of those caring for individuals with mental illness and behavioral disorders were receiving respite.

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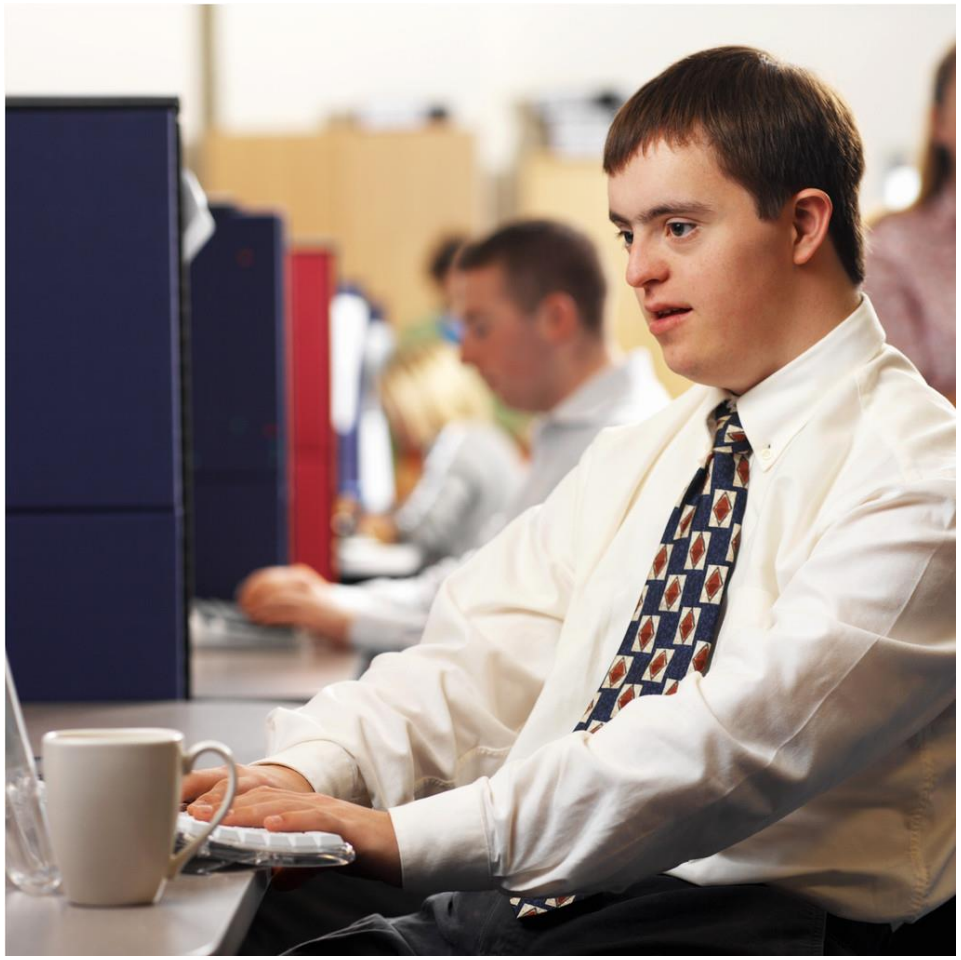
…. And Too Late

- Of those who do, they receive too little respite, often too late.
- Respite should be meaningful for the individual with a disability, for the caregiver, for the family.



Respite Barriers

- Affordability Issues
- Limited providers or respite options
- Limited knowledge of resources
- Reluctance to identify as caregiver or ask for help
- Confusing and restrictive eligibility criteria imposed by multiple funding streams

Multiple Funding Streams

- Medicaid Waivers
- Medicaid State Plan Options
- VA Respite Services
- National Family Caregiver Support Program
- Block Grants (e.g., Social Services, Children's Mental Health)
- Other Federal Categorical Funding Streams
- State Respite, Family Support or Caregiver Support Programs

Federal Lifespan Respite Program

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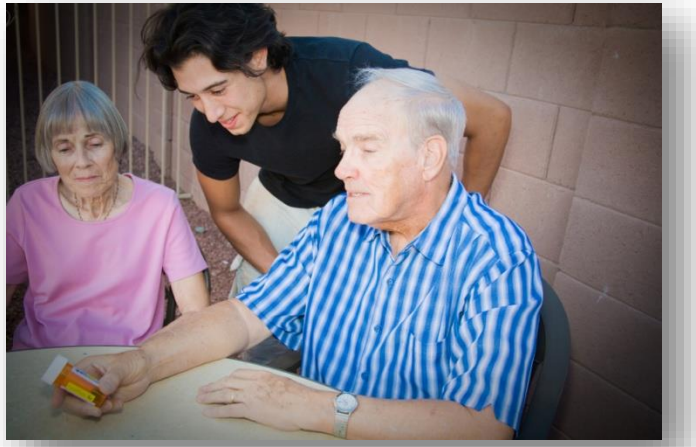
Lifespan Respite … not just care or a service, but…..

Lifespan Respite Definition:

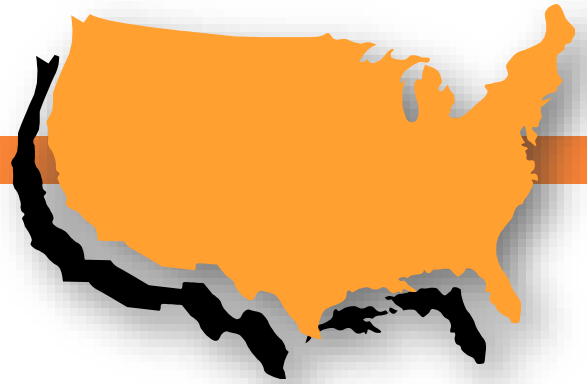
- Coordinated ***SYSTEMS*** of accessible, community-based respite services for all family caregivers regardless of age or special need.



Characteristics of Lifespan Respite Programs

- 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 *new* respite services
- Connect families to respite services, providers, and payment resources
- Recruit and train respite providers
- Promote public awareness about respite

Moving to National Scale



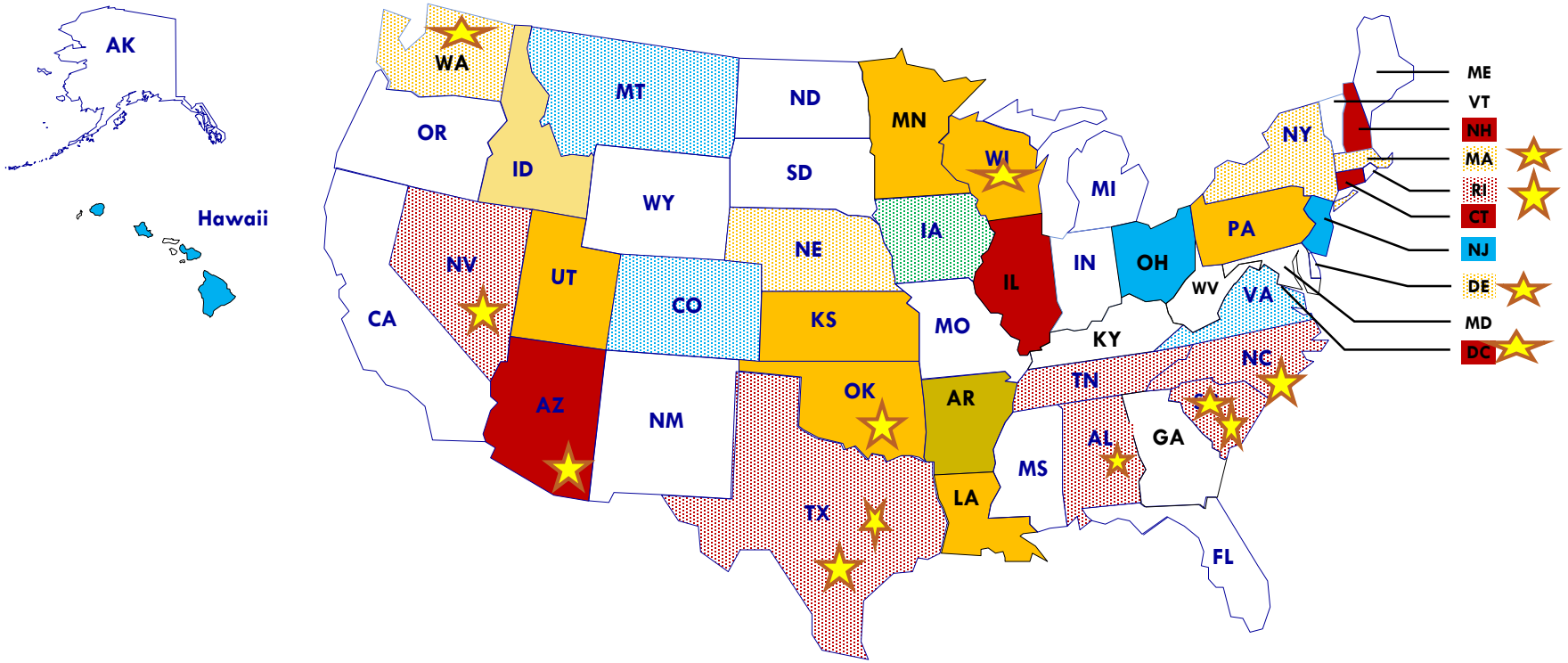
- Lifespan Respite law signed in 2006
- Funded for the first time in 2009 at $2.5 million
- Level funded each year

Federal Lifespan Respite Care Program

US Administration for Community Living administers competitive state grants for mandatory uses 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

Lifespan Respite States



2009 Lifespan Respite States

2010 Lifespan Respite States

2011 Lifespan Respite States

2012 Lifespan Respite States

2013 Lifespan Respite State

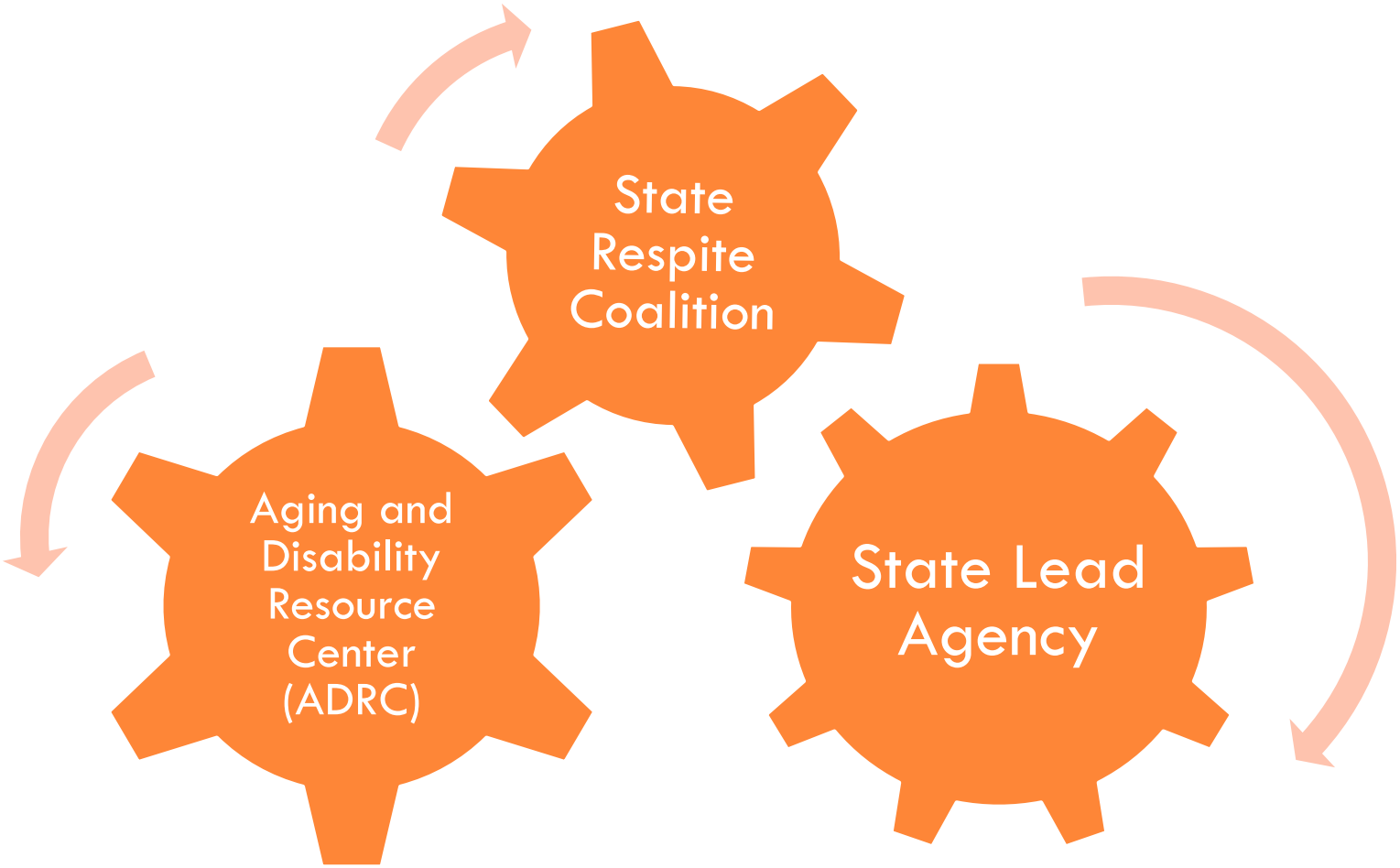
2014 Lifespan Respite State

2012 & 2013 Integration & Sustainability Grantees

2014 Long-Term Sustainability

Courtesy of Greg Link, ACL/AoA

Lifespan Respite Built on Collaboration



From Barriers to Building Blocks

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

Innovations & Promising Practices

- Respite Registries and Databases
- Marketing and Outreach Campaigns
- Emergency Respite
- Volunteer and Faith-based Initiatives
- Respite Voucher & Service Delivery Models
- Mini-Grant Programs
- Respite Provider Training and Recruitment

Collaborating to Build Services and Natural Supports for Underserved Families

North Carolina Lifespan Respite Project

- Awarded 9 mini-grants to community-based agencies to serve targeted gap populations (between $5k and $20k each)
  - Provided 14,126 hours of respite to 235 new families
  - Trained 86 volunteers
  - 12 new or enhanced services have been sustained (summer camps, private pay options, volunteer teams)
- Money Follows the Person partnership resulted in two family caregiver to caregiver peer mentoring and respite volunteer projects.

Delaware Lifespan Respite Network

- Spearheaded by Delaware Caregiver Coalition in 2003; administered by Easter Seals of DE and Eastern Shore.
- Serves children and adults with special needs or disabilities.
- Local foundation funding for families not eligible for other respite funding.
- Provides families with small grants up to $500 per recipient per calendar year.

Tennessee Respite Coalition

- Tennessee Respite Coalition administers a Family Directed Respite Program utilizing federal and state funding streams
- Each family completes a Family Respite Plan with goals and objectives for respite and dates of completion.

ARCH Resources

ARCH Resources and Tools

- Phone and Email Technical Assistance
- Fact Sheets
- Guidebooks
- Webinars
- State Lifespan Respite Summits
- ARCH Quick News Updates
- National Respite Locator Service

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ARCH Focus

In collaboration with ACL/AoA:

- Performance Measurement and Data Collection
- Promoting Respite Research
- Emerging Practices Database

How to Get Involved

- Provide input to your State Lifespan Respite Program
- Participate in State Respite Coalition
- Help start a coalition

For More Information

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This project is supported, in part, under a grant from the U.S. Department of Health and Human Services, Administration for Community Living, Administration on Aging. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. These contents, however, do not necessarily represent the policy of the U.S. Department of Health and Human Services and endorsement by the Federal government should not be assumed.

Networking with NAPP

(National Association of PASRR Professionals)

http://www.pasrr.org/about.aspx

- Networking with NAPP is a follow up discussion on the webinar.
- The next Networking with NAPP session is:

Tuesday, December 23rd , 2014

1 PM EST

To register for the session, please contact Betty Ferdinand: (bferdinand@cii.us.com).

A reminder invite will be sent to all webinar participants.

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