



# Hitting the High Notes with Lifespan Respite: Progress at the Five-Year Point

16<sup>th</sup> Annual National Lifespan Respite Conference

October 9, 2014



# Overview

- The Administration for Community Living (ACL)
- ACL and the Lifespan Respite Program
- Program status – Progress at the Five-Year Point
  - Accomplishments, outcomes & lessons learned
  - Looking ahead

*"Our goal is for all Americans to live healthier,  
more prosperous, and more productive lives."*

*- Secretary Kathleen Sebelius*



"For too long, too many Americans have faced the impossible choice between moving to an institution or living at home without the long-term services and supports they need. The goal of the new **Administration for Community Living** will be to help people with disabilities and older Americans live productive, satisfying lives."

*Secretary Kathleen Sebelius*

## About ACL

- The Administration for Community Living (ACL) is an operating division within the U.S. Department of Health & Human Services which brought together:
  - the Administration on Aging (AoA)
  - the Office on Disability (OD)
  - the Administration on Developmental Disabilities (ADD)
- ACL is charged with developing policies and improving supports for seniors and persons with disabilities of all ages.

# Background

HHS established ACL to achieve several important objectives:

- Reduce the fragmentation that currently exists in federal programs addressing the community living service and support needs of older adults and persons with disabilities
- Enhance access to quality health care and long-term services and supports for all individuals
- Promote consistency in community living policy across other areas of the federal government
- Complement the community infrastructure, as supported by Medicaid and other federal programs, in order to better respond to the full spectrum of needs among these populations

# ACL's Mission & Vision

## Mission

- Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

## Vision

- All people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society.

# ACL Today: Authorizing Statutes & Programs

- **Older Americans Act of 1965** (as amended)
- **Public Health Service Act Programs**
  - Section 398 – Alzheimer’s Disease Supportive Services Program (ADSSP)
  - Title XXIX – Lifespan Respite Care Program
- **Health Insurance Portability and Accountability Act of 1996** (HIPAA) – Health Care Fraud and Abuse Control (HCFAC) funds
  - Senior Medicare Patrol
- **Developmental Disabilities Assistance and Bill of Rights Act of 2000** (DD Act)
- **Help America Vote Act (HAVA)**

# ACL & Lifespan Respite – A perfect fit!

- ACL and Lifespan Respite Program Objectives
  - Addresses fragmentation of (respite) programs and services
  - Focus on (respite) quality improvement
  - Cross-(respite)program/policy focus
  - Improve response to the (respite) needs of families
- Works across age and disability populations to maximize independence and well-being
- Family support as a key objective





# **THE LIFESPAN RESPITE PROGRAM**



# Federal Lifespan Respite Care Program

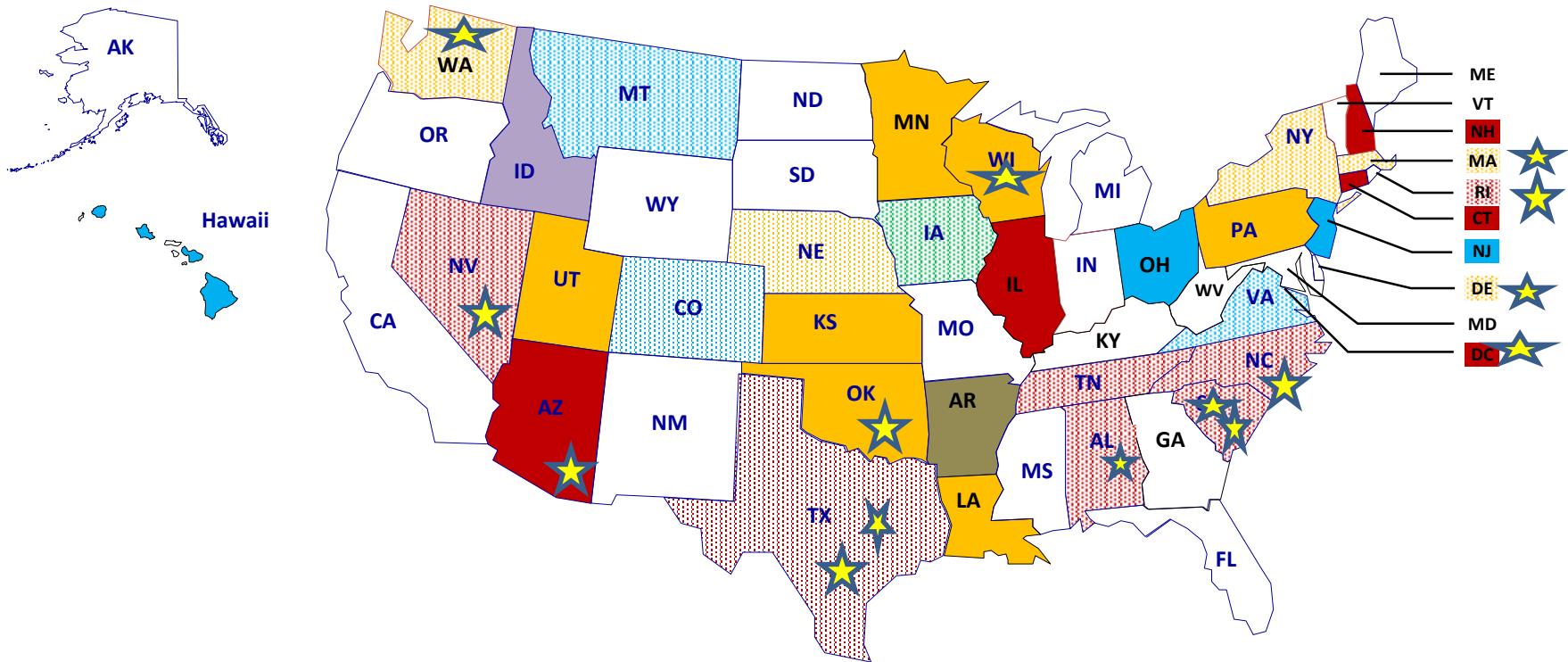
ACL/AoA administers competitive state grants for mandatory uses of the funds:

- 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 Program Status

- 32 states and DC funded since 2009
  - Up to \$200,000 for initial three year projects
  - Expansion supplements - 10 states (FYs 11 & 12)
- Technical Assistance Resource Center (FY 09 & 12)
- FY 2012 & 2013– Integration and Sustainability Grants
  - Up to \$250,000 each/18-month projects
  - Builds on the initial three-year grant
  - Focus on integrating respite/caregiver supports and sustainable approaches
- FY 2014 – One New State/16 Building Long-Term Sustainability

# Lifespan Respite States (as of 2014)



- 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

# Evolving Focus of Grantee Activities

Basic Infrastructure	Service Delivery Performance Measurement	Systems Integration & Long-Term Sustainability
<ul style="list-style-type: none"> <li>• Environmental Scans &amp; Needs Assessments</li> <li>• Coalition building</li> <li>• Partnership development</li> <li>• Statewide strategic planning</li> <li>• Marketing, outreach, public awareness campaigns</li> <li>• ADRC expansion</li> <li>• Respite registry development/expansion</li> <li>• Volunteer &amp; faith-based efforts</li> <li>• New partnerships with higher education</li> <li>• Caregiver education</li> </ul>	<ul style="list-style-type: none"> <li>• Development of new service delivery models (e.g., vouchers, emergency respite programs)</li> <li>• Mini-grants to foster local solutions and innovation</li> <li>• Initial development and testing of performance and outcome metrics</li> <li>• Provider recruitment and training</li> <li>• More than 2000 family caregivers across the age and disability spectrum received respite services</li> </ul>	<ul style="list-style-type: none"> <li>• Public/private partnerships to support community living</li> <li>• Integration of respite across state LTSS programs</li> <li>• Outreach to/inclusion of employers</li> <li>• Greater focus on rural, minority, underserved populations</li> <li>• Improved linkages with critical pathways for family caregivers</li> <li>• Coalition visibility and empowerment for better advocacy</li> <li>• Measuring systems change</li> </ul>

# What have we learned so far???

- It takes time....
- Partnership, partnership, partnership
- Look to model approaches
- Stay flexible
- Performance measurement from day one
- Sustainability focus from the beginning



**LOOKING AHEAD**



# Program Sustainability

- Engage grassroots/community
- Embed grant activities into ongoing state LTSS reform efforts
- Grow and support State Respite Coalition to focus on sustainability
- Long-term strategic planning
- Supported through current TA efforts



# Performance Measurement

- Need to demonstrate program success and progress
- Determine appropriate measures
  - Systems Change
  - Consumer Outcomes
- New reporting framework (eventually)
- Ongoing Technical Assistance



# Building an Evidence-Base for Respite

- Expert Panel on Respite Research
- Annotated bibliography
- Recommendations for the future of respite research
- ARCH database of promising practices in respite

# Contact Information

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