

# 2012 HCBS LEARNING SYMPOSIUM: LIFESPAN RESPITE PROGRAM MEETING

2012 National HCBS Conference

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## CONVENORS:

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Program Director  
ARCH National Respite Network &  
Resource Center

# Agenda

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- Welcome and Introductions – All
- Strategies for Ensuring Sustainability – Jill
- Performance Measurement/Data Collection – Greg
- Program Status & Looking Ahead – Greg/Jill
- Open Discussion – All

# WELCOME AND INTRODUCTIONS



# Introductions

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- Name
- State
- Grant Year
- Key Accomplishment
- Key Challenge

# STRATEGIES FOR ENSURING SUSTAINABILITY



# Webinar Part I: Introduction to a Framework for Sustainability Planning

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- Provided a framework that grantees and their partners can use to design sustainability plans.
- Help grantees and their partners consider how to benchmark their progress toward sustainability.
- Provide tools to support the development of a strategic financing plan.

# Pillars of Lifespan Respite

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- **Coordination**
- **Collaboration**
- **Funding Streams and Partnerships as Building Blocks**

# Federal Funding and Support Opportunities for Respite

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- Identified over 60 federal programs to:
  - ▣ help families pay for respite
  - ▣ help states build respite capacity
  - ▣ support training and infrastructure
- Potential Funding Sources
- Blueprint for identifying potential partners



# Outside the Box” Respite Funding

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- Child Health Insurance Program
- Community Development Block Grant
- Social Services Block Grant
- Senior Companion Program
- Community-Based Child Abuse Prevention
- Money Follows the Person

# Not Just about Federal Funding...or even Just about Funding

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## Money...

- Private Foundations and Corporate Funding
- State Funding
- Fundraising

## Other Resources....

- In-Kind Support
- Sharing Respite provider lists, training curricula, recruitment tools
- Sharing staff
- Reducing administrative burdens

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# Questions

## Lifespan Respite Sustainability

# Your Lifespan Respite Program

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- Can you briefly describe your state's Lifespan Respite infrastructure or coordinated system?
- How does it differ from other initiatives that focus on caregiving in your state?
- How does it complement those initiatives?
- What exactly are you trying to sustain?

# Sustainability Plan

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- Has your state developed a sustainability plan?
- If so, what are the major plan components and strategies?

# Partnerships

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- Who are your partners?
- What are your partners contributing to your Lifespan Respite program in terms of existing resources, expertise, time or money?

# Funding

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- Do you know how much it will cost and what resources you need:
  - ▣ to support your state Lifespan infrastructure?
  - ▣ to develop new services or pay for respite?
  - ▣ for provider training and recruitment?
- What federal, state or private funding sources have you used or do you plan to use for these initiatives?

# PERFORMANCE MEASUREMENT & DATA COLLECTION





# Performance Measurement Data Collection

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- Lifespan Respite Data Workgroup - Goals
  - ▣ High level recommendations for data and performance
  - ▣ Develop some level of uniformity
  - ▣ Inform ACL/AoA's development of a performance measurement/outcomes framework
- Products:
  - ▣ Fact Sheet/White Paper
  - ▣ Data Collection Package for OMB approval
- Guiding Principles
  - ▣ Organic in nature
  - ▣ Collaborative
  - ▣ Consensus

# Performance vs. Evaluation

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## **Performance Measurement**

- Goal related reporting of accomplishments
- May reflect process, outputs, or outcomes
- Is the program doing what it is supposed to do?
- Supports decision making and resource allocation
- Ongoing management tool

## **Evaluation**

- Ad Hoc/Periodic
- Uses experts external to the program
- Focus on program achievement of objectives
- Looks at the broader context of program implementation

# Lifespan Respite Act - Purpose

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- Expand and enhance respite services
- Improve dissemination and coordination of service
- Provide, supplement or improve access and quality of respite services

# Systems vs. Consumers

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## **Systems Measures**

- ❑ Public Awareness
- ❑ Referral Mechanisms
- ❑ Waiting Lists
- ❑ Service Gaps
- ❑ Volunteer/Paid Providers
- ❑ Coordination
- ❑ Out-of-Home placement

## **Consumer Measures**

- ❑ Care Recipient Information
- ❑ Population Measures
- ❑ Service Definitions
- ❑ Service Use (freq/dosage)
- ❑ Participant Direction
- ❑ Perceived Quality of Life
- ❑ Consumer Expectations

# Systems Development Measures

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- Referral Mechanisms & Pathways
- Achievement of a Lifespan Approach
- Available Respite Options
- Reduction in Placement
- Cost savings

Are these on track?

Key Indicators and Domains?

What are we missing?

# Consumer Measures

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- Demographics (Caregivers & Care Recipients)
- Service Use (Units, Type, Duration, Use)
- Consumer Outcomes (Stress Reduction, Health)

Are these on track?

Key Indicators and Domains?

What are we missing?

# PROGRAM STATUS FUTURE DIRECTIONS



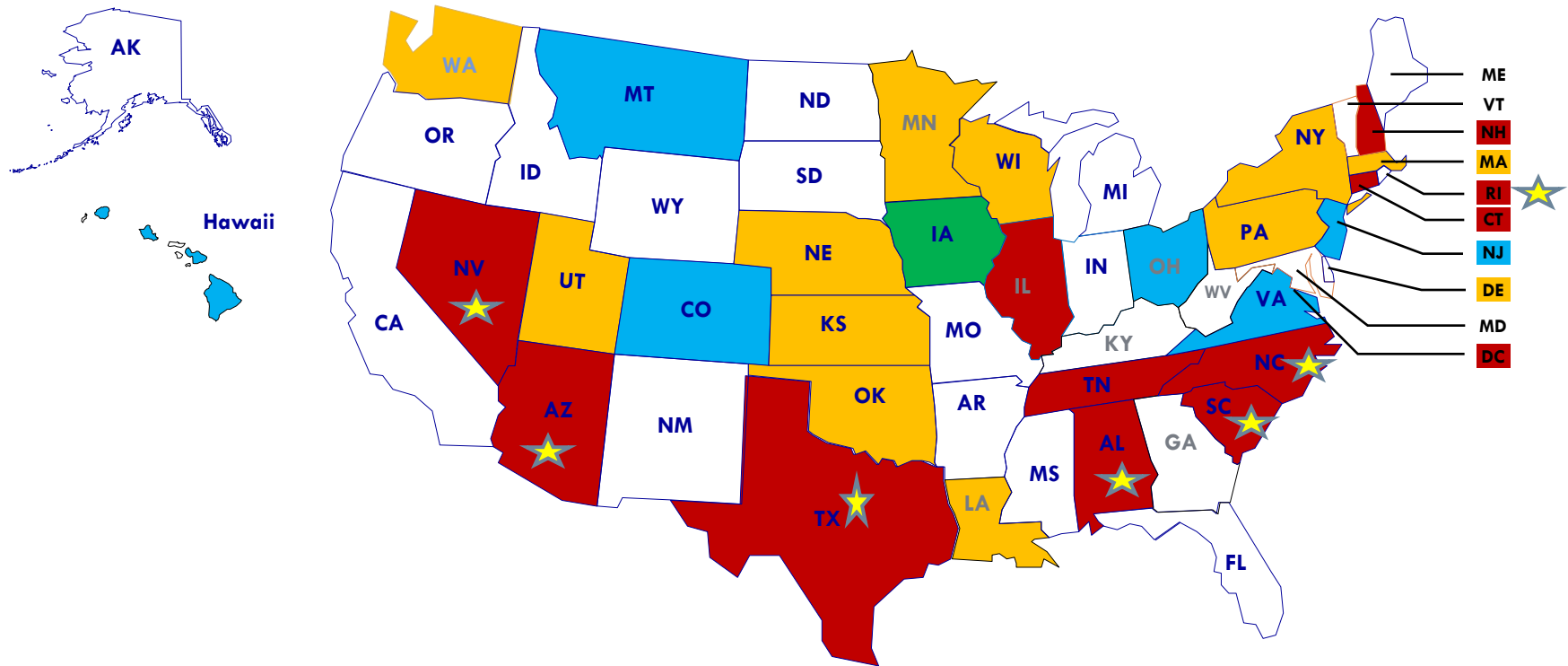
# Four Years of Progress

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- Competitive Grants to States 2009 - 2012
  - 30 States and DC
  - Three-year projects
- TA Resource Center (2009 & 2012)
- FY 2011 & 2012 Expansion Grants
- For FY 2012
  - New State
  - Integration & Sustainability Grants
  - Expansion Grants
  - New TA Resource Center



# Lifespan Respite States



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

# Innovations & Promising Practices

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- Environmental Scans/Needs Assessments
  - ▣ Basis for future legislation/funding
  - ▣ State Respite and Strategic Planning
- Marketing and Outreach Campaigns
  - ▣ Just One More (NC)
  - ▣ Give Caregivers a Hand (AZ)
- Volunteer Programs
  - ▣ Time Banks Model
  - ▣ Faith-based

# Innovations and Promising Practices

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- Respite Voucher & Service Delivery Models
  - Establishment of new voucher programs
  - Mobile respite
  - Respite Events
- Mini-Grant Programs
  - Seed money
  - Local focus

# Lessons Learned

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- It takes time....
- Build on model approaches
- Partnerships are essential
- Flexibility is key
- Focus on Sustainability
- Provide Support and Technical Assistance
- Performance measurement from day one

# Looking Ahead - Nationally

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- Reauthorization
- FY 2013 Appropriations (and beyond)
- Ongoing Program Development & Refinement
  - ▣ Infrastructure development
  - ▣ Focus on service provision
  - ▣ Data collection
  - ▣ Performance measurement
  - ▣ Sustainability
  - ▣ Technical assistance

# What Next?

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- What challenges do you see on the horizon? How can we help?
- Where would you like to see ACL/AoA move with respect to how the program is implemented?
- What TA needs do you currently have? Foresee?

# OPEN DISCUSSION



# Open Discussion & Dialogue

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- Maximizing Expansion Funds
- Partnering Opportunities
- Current Reporting Requirements
- Making the most of Environmental Scans
- Other Burning Issues



# Contact Us

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