



Exemplar Lifespan Respite States: An Experiment in Sustainability Planning

**Home and Community Based Services Conference
September 16, 2014**

Presenters

Jill Kagan, MPH

ARCH National Respite Network and Resource Center

Todd Coffey, Acting Director

CO Aging and Adult Services

David Besst, Program Services Manager

AZ Division of Aging & Adult Services

Family Caregiving in the US

3

- 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



Family Caregiving is Lifespan!

4

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.

Sources: *Caregiving in the U.S. 2009*. Bethesda, MD: National Alliance for Caregiving and Washington, D.C.: AARP, 2009. and Lynn Feinberg, L., Reinhard, Susan, C, Houser, A. and Choula, R. (2011). *Valuing the Invaluable: 2011 Update The Growing Contributions and Costs of Family Caregiving, 2011 Update*, AARP Public Policy Institute Issue Brief Insight on the Issues, Washington, DC: AARP

Respite is...

5

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

6

- 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 foster care, nursing home or other out-of-home placements.

Respite: Too Little, Too Late

7

- 89% of family caregivers do not receive respite.
- Of those who do, they receive too little, often too late.
- Respite needs to be meaningful for caregivers, as well as care receiver.



Respite Barriers

8

- Affordability
- Too few trained providers or respite options
- Reluctance to identify as caregiver or ask for help
- Multiple Funding Streams
- Confusing and Restrictive Eligibility Criteria

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

9

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

10

- 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

11

Federal Lifespan Respite Program



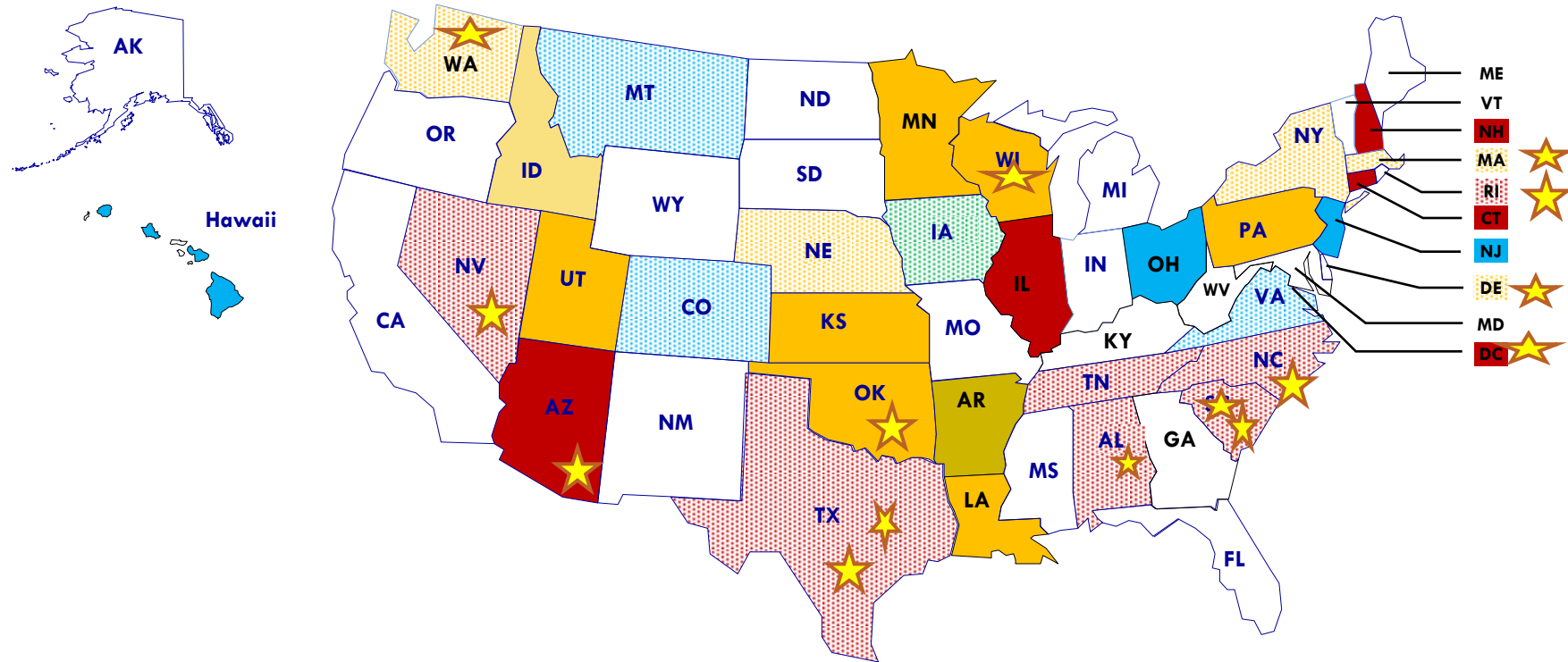
Federal Lifespan Respite Care Program

12

US Administration for Community Living, Administration on Aging 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 (as of 2014)

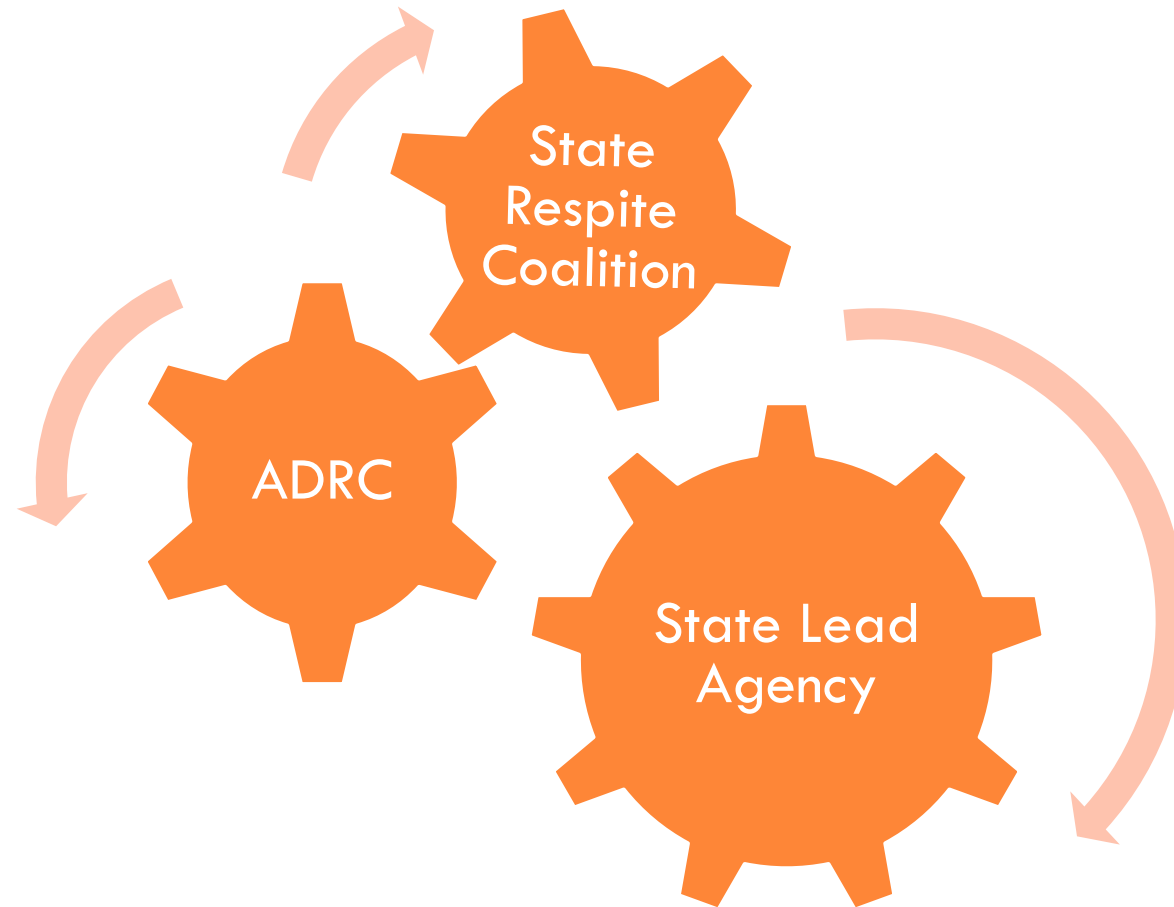


- 2009 Lifespan Respite States
- 2010 Lifespan Respite States
- 2011 Lifespan Respite States
- 2012 Lifespan Respite States

- 2013 Lifespan Respite State
- 2014 Lifespan Respite State
- 2012 & 2013 Integration & Sustainability Grantees
- 2014 Long-Term Sustainability

Lifespan Respite Built on Collaboration

14



Lessons Learned

15

- It takes time....
- Build on model approaches
- Partnerships are essential
- Flexibility is key
- Performance measurement from day one
- Sustainability focus is critical from the outset

Exemplar States for Sustainability

16

- Partnership with The Finance Project
- Eight States Selected (AL, IA, LA, MA, NE, NH, PA, VA)
- Sustainability Toolkit
- Individualized Technical Assistance

Emerging Themes in Sustainability

17

- Engage grassroots/community
- Embed grant activities into ongoing state efforts
- Forge state agency fiscal partnerships
- Grow and support State Respite Coalition to focus on sustainability
- Plan long-term

For More Information

18



Jill Kagan
ARCH Program Director
703.256.2084

jkagan@archrespite.org

ARCH National Respite Network and Resource Center

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

Lifespan Respite Technical Assistance Center

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.





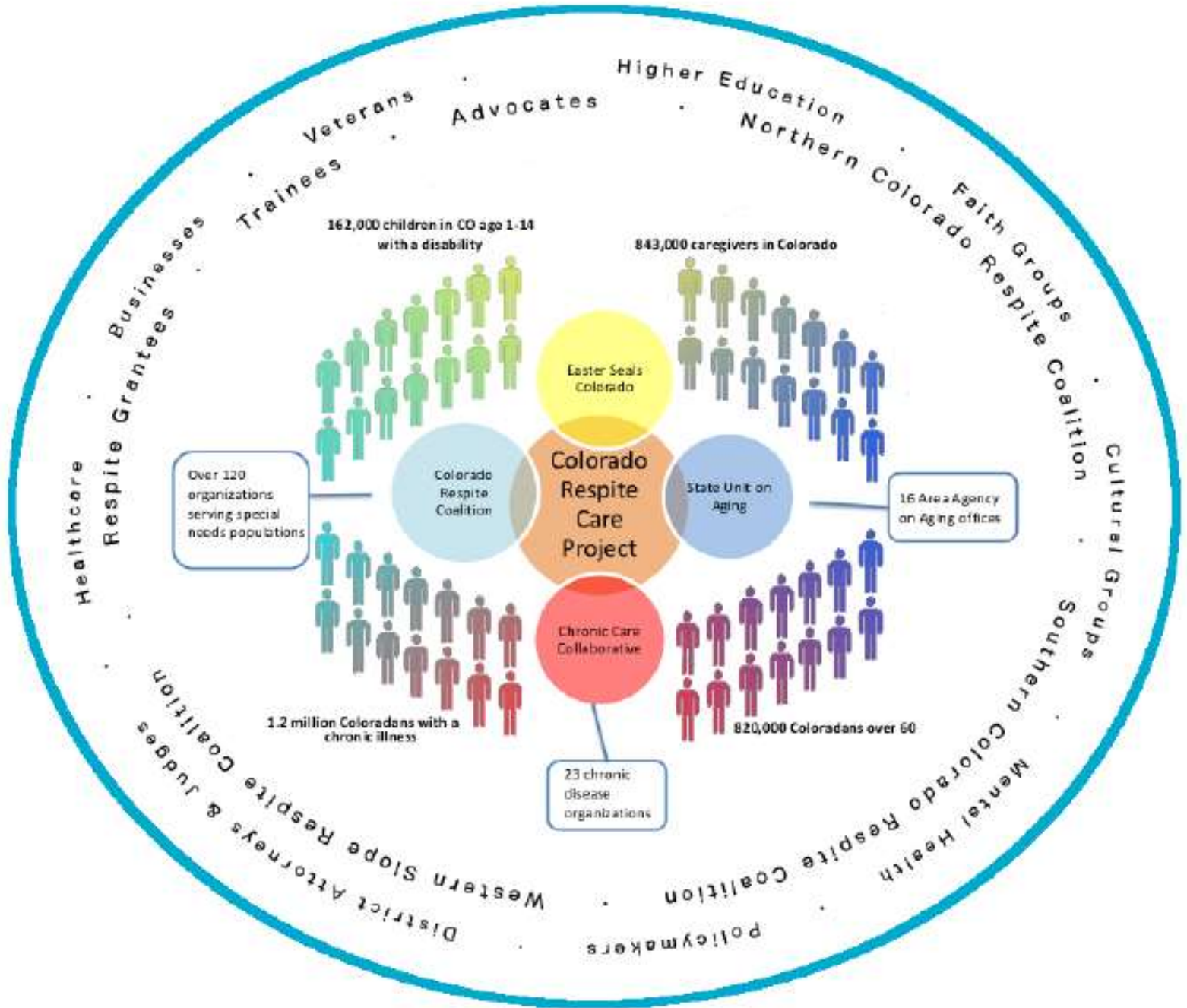
Colorado Respite Care Project

NASUAD HCBS Conference
September 2014

Todd Coffey, Acting Director
Aging and Adult Services
1575 Sherman St.
Denver, CO 80203
303-866-2750

Partnerships

- Colorado Respite Coalition
 - Over 120 Organizations
- Chronic Care Collaborative
 - 28 Organizations
- Easter Seals Colorado
- Colorado State Unit on Aging



Impact to Date

- Website Launched in 2012
 - www.coloradorespitecoalition.org
 - Financial Assistance
 - Training Resources
 - Respite Locator
 - On-Line Database
 - 450 Providers
 - Provider Registration
 - Project Announcements

Impact to Date

- Expanded Training
 - Trainings – 3,100+ trained, statewide (urban and rural), covering lifespan care for all disabilities
 - Local University Partnership for College Credit to Students Working in Field
 - Participants
 - Caregivers
 - Professional Providers
 - Community Members
 - Volunteers Students

Impact to Date

- **Advocacy**
 - In 2012, HB12-1226 Passed Imposing Surcharge on those Convicted of Committing Crimes Against At-Risk Populations
 - State General Funds Allocated to Support Respite
 - \$150,000 in 2013
 - \$250,000 in 2014

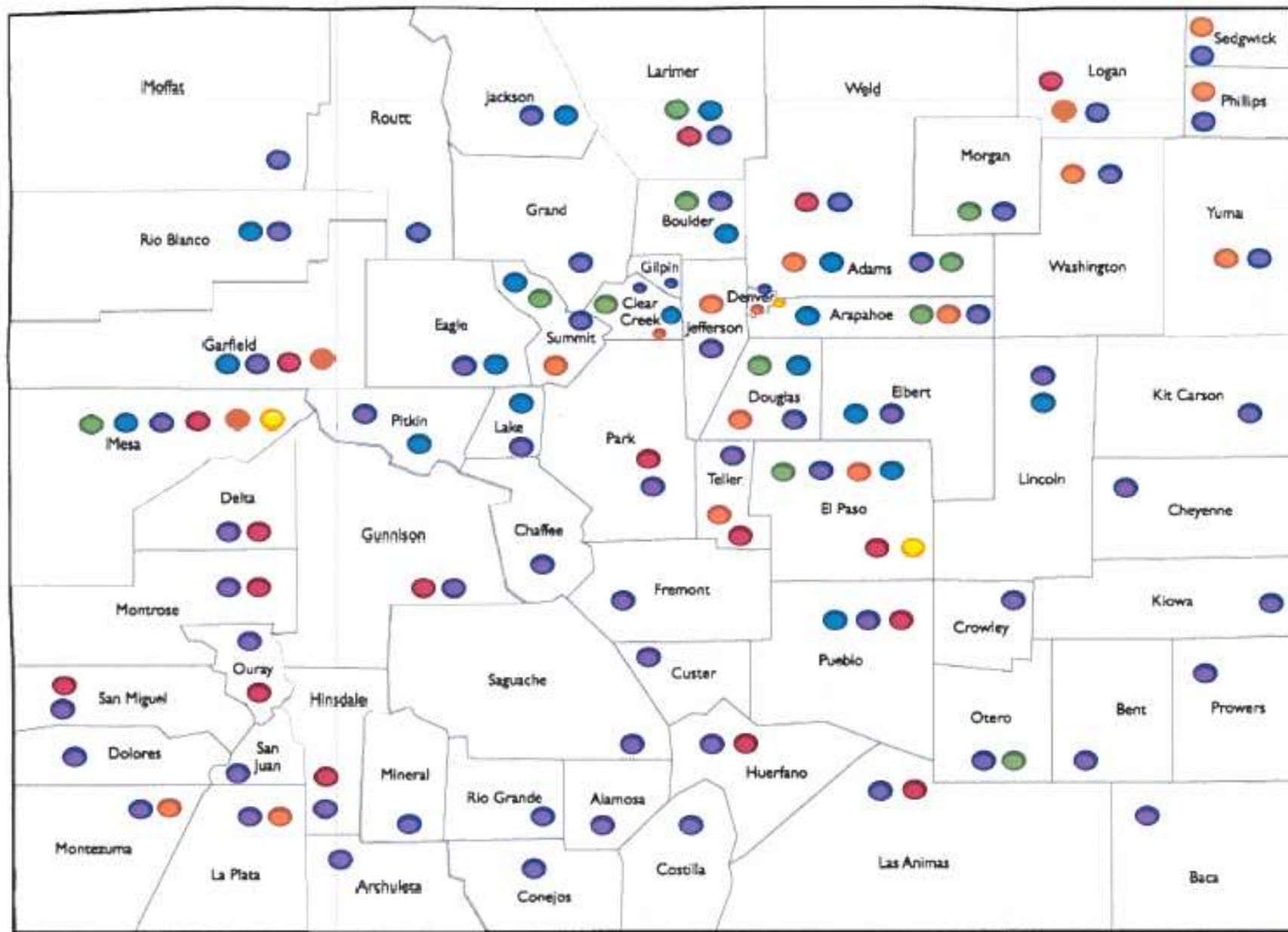
Impact to Date

- State General Funds and Federal Grant Funds
 - Reduced Service Gaps
 - 28 Grants (\$1,000 to \$27,000)
 - Total \$146,950
 - Statewide
 - Lifespan Care
 - Range of Disabilities
- Outreach and Education
 - District Attorneys
 - Judges
 - AAAs
 - ADRCs
 - Providers
 - Caregivers

Impact to Date

- Hosted Three Summits in 2013
 - Attendees Respite Stakeholders
 - Identified Gaps in Respite Resources
 - Result: Formation of Three Regional Respite Coalitions
 - Northern Colorado Respite Coalition
 - Southern Colorado Respite Coalition
 - Western Slope Respite Coalition

Colorado Respite Care Project Activities - 2011 – 2014



● Trainings
 ● Grantees
 ● Regional Respite Coalition Members
 ● District Attorneys Visited
 ● Summit Locations
 ● Information Disseminated

Resource



I-844-COL-ADRC

(1-844-265-2372)



**Todd Coffey,
Acting Director
Aging and Adult Services**

QUESTIONS

Arizona Lifespan Respite Care Program

“A Seven Year Path to Sustainability”

NASUAD HCBS Conference
September 2014

David Besst
Program Services Manager
AZ Division of Aging and Adult Services
1789 W. Jefferson St.
Phoenix, AZ 85351
602-542-6431

Arizona Lifespan Respite Care Program

- Arizona Legislature passes statute authorizing program in 2007
- Designed after the federal law
- Appropriated \$500,000 for services and an FTE to administer development of the program





Federal Lifespan Respite Care Program

In 2009 the US Administration on Aging administers competitive state grants for these mandatory uses of the funds:

- Development or enhancement of State and local Lifespan Respite systems
- Provision of planned or emergency respite for all ages

Arizona Lifespan Respite Care Program

- Arizona funded in first round (2009)
- Key Deliverables of grant:
 - Development of Caregiver Assessment Tool
 - Public Awareness Campaign
 - Statewide Resource Line for Caregivers

Arizona Lifespan Respite Care Program

- Caregiver Assessment Tool
 - Collaborative Development Process
 - Based on existing assessment of C/R
 - Implemented and now required when authorizing respite within Aging Network

Arizona Lifespan Respite Care Program

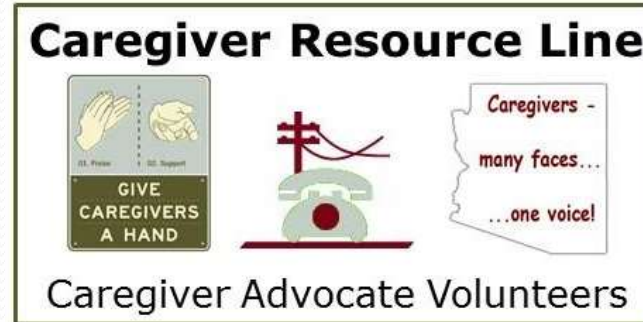
- Public Awareness Campaign
 - Educate public about scope
 - Encourage self-identification of family caregivers
 - Inspire support from individuals and legislators alike
 - Launched campaign as part of national event



***The
Many Faces
Of Respite!***

2011 National Lifespan Respite
Conference and Grantee Meeting

Arizona Lifespan Respite Care Program



- Volunteer based Hotline
- Answered live during business hours
- After hours calls recorded and returned in 1-2 days (3 referrals)
- Staff trained and coordinated by grant funded worker (will be ACC staff)
- Partnership between State Unit on Aging and the Arizona Caregiver Coalition



Arizona Lifespan Respite Care Program

- Caregiver Resource Line



- Currently averages 10 -15 calls a day
- Serves as the “caregiver specific” component of AZ Links
- Total of 12 volunteers currently trained as “Caregiver Advocates”

Arizona Lifespan Respite Care Program

- Integration & Sustainability Grant Awarded in August, 2012
 - 26 month project period, after no-cost extension to 9/30/2014
- Key Deliverables
 - Arizona Respite Vouchers
 - Online Arizona Respite Locator
 - Adapt and expand use of CAT
 - Continue partnership with AZ Links

Arizona Lifespan Respite Program Integration and Sustainability

- Arizona Respite Voucher
 - Pilot process started in late 2013
 - CRL taking intake calls, pre-screens, and conducting CAT interviews
 - Vouchers issued quarterly for up to \$300, max total for year is \$1,200
 - AAAs issue the reimbursement checks
 - Ongoing program to start 10/1/14
 - Various funding streams utilized

Arizona Lifespan Respite Program Integration and Sustainability

- Arizona Respite Locator
 - Partnership with Rewarding Work
 - www.rewardingwork.org
 - Website went live in Nov. 2013
 - www.arizonarespitelocator.org
 - Adding new portal for DDD clients
 - Sustainability support from AAAs and DD Planning Council

What is the future of Arizona's Lifespan Respite Program?



Now a 501 (c) 3



DEPARTMENT OF ECONOMIC SECURITY

Your Partner For A Stronger Arizona



Questions?

For More Information

- Arizona Caregiver Coalition
www.AZCaregiver.org
www.ArizoanRespiteLocator.org
- ARCH National Respite Network and Resource Center (Technical Support agency for LRP)
www.archrespite.org