



Diverse Partnerships to Advance Lifespan Respite Opportunities for Family Caregivers

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Presenters

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Overview

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- National picture of family caregiving in the U.S.
- Challenges to accessing respite services
- Collaboration in the Lifespan Respite Care Program
- Maryland's History of Collaboration
- Maryland's Lifespan Respite grant and key partnerships
- Status of Grant Activities

Family Caregiving in the U.S.

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- More than 43 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition.
- 80% of those needing long-term services and supports in the U.S. are living at home.



Sources: 1) *Caregiving in the U.S. 2015*. Bethesda, MD: National Alliance for Caregiving and AARP Public Policy Institute.
2) *Rising Demand for Long-Term Services and Supports for Elderly People*, CBO, June 2013

Effects of Family Caregiving

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- Many derive spiritual, emotional and even physical benefits. For others – high stress leads to poor physical/emotional outcomes. (*Population Reference Bureau, 2016*).
- 4 in 10 caregivers consider their caregiving situation to be highly stressful (*2015 Caregiving in the US, NAC/AARP*).
- Family caregivers providing substantial assistance with health care experience significant emotional, physical and financial difficulty. (*Wolff, 2016*).

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

Benefits of Respite

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- ❑ Improves family caregiver stress levels, which in turn, benefits 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.
- ❑ Gives care recipient a break, too!

Respite: Too Little, Too Late

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- 85% of family caregivers of adults do not receive respite (2015 *Caregiving in the US, NAC/AARP*).
- Of those who do, they often receive too little, too late.



Respite Barriers

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- Limited Resources
- Cost
- Shortage of qualified providers
- Limited respite options or appropriate programs
- Reluctance to use respite, ask for help, or self-identify as caregiver
- Access issues
 - ▣ Multiple funding streams with confusing and restrictive eligibility
 - ▣ Lack of information

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

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Lifespan Respite Definition:

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



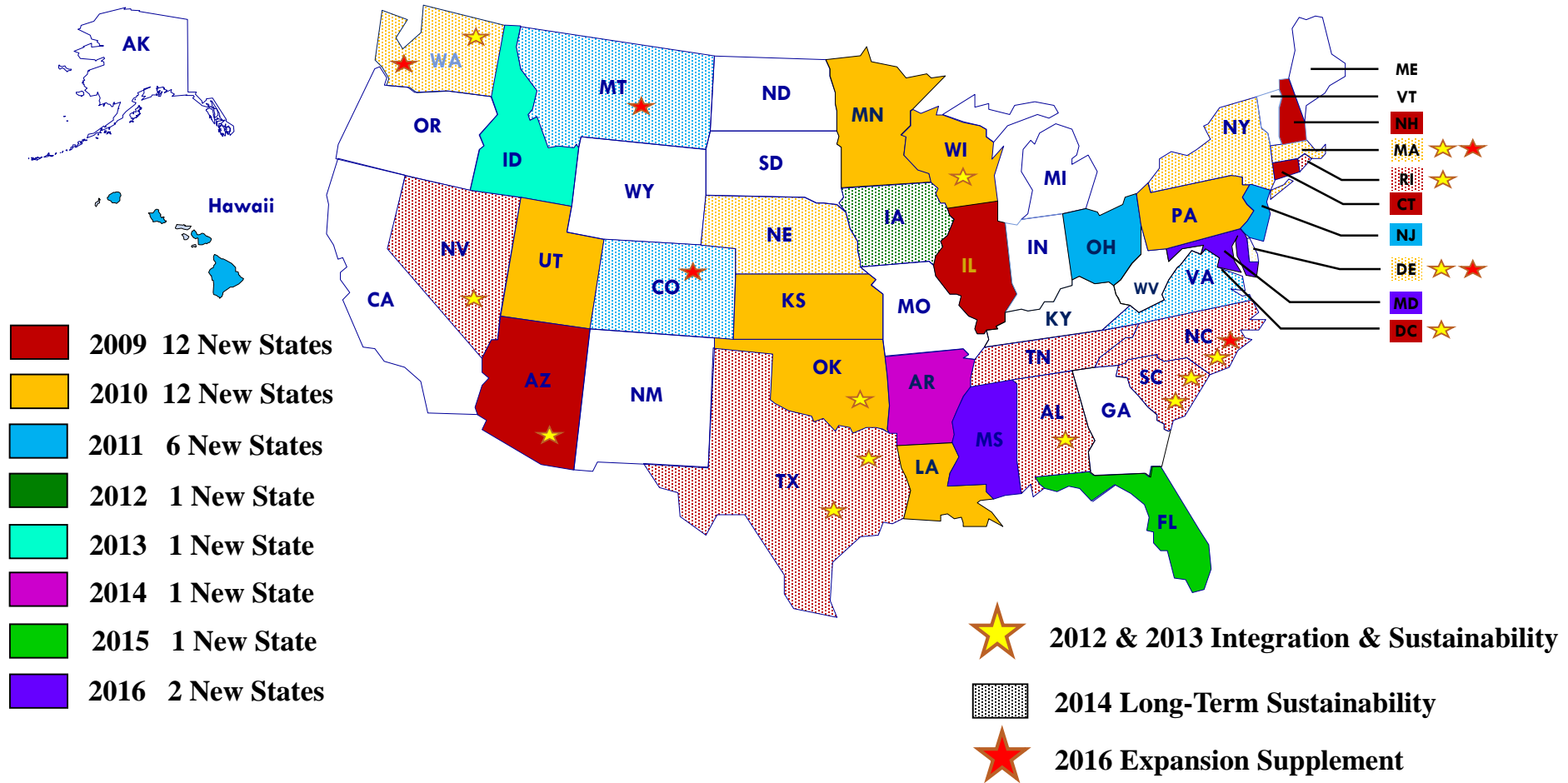
Federal Lifespan Respite Care Program

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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



Evolving Focus of Grantee Activities

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Lifespan Respite Built on Collaboration

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Maryland's Strategies for Addressing Lifespan Respite Care and Family Caregiver Supports

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- Respite Aware Day – First Annual September 1998
- Maryland Respite Care Coalition – 1999
- Maryland Caregiver Support Coordinating Council – 2001

Maryland's Strategies for Addressing Lifespan Respite Care and Family Caregiver Supports

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- Challenges and bumps along the way
- Successes
- Today's landscape

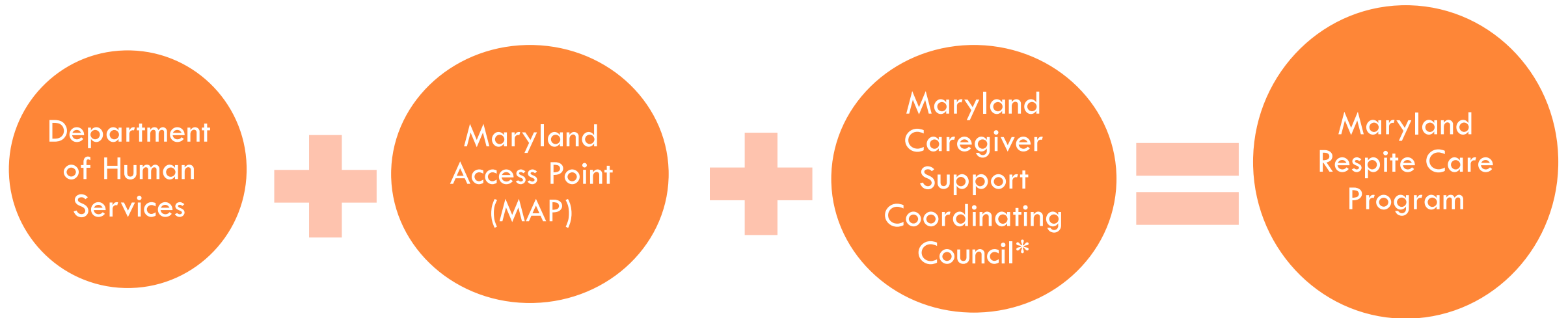
Maryland's 2016 Respite Care Grant Proposal: A Collaborative Effort

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- 2014-2015 Caregiver Survey Results
- Engaged Partnership Network in Dialogue
 - In person and via teleconference
 - Solicit feedback about systems infrastructure, non-negotiables
 - Informed goals, objectives, and outcomes
- Convened workgroups
 - Volunteers from partnership network
 - Committed staff from state agencies (Departments of Health, Human Services, Aging, and Disabilities)

Maryland's Respite Care Grant Proposal: Framework

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*Until the Maryland Respite Care Coalition can reconvene

Maryland's Respite Care Grant Proposal: Ambitious Interventions

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- Creation of an universal respite care services application and a robust data management system to streamline identification of appropriate services across various programs
- Establishment of “info-social” models statewide to offer caregivers social and training opportunities as well as offer care recipients a safe and enjoyable experience
- Development of well-qualified respite care providers and expand capacity of volunteer options through faith-based organizations and postsecondary education programs
- Formation of a statewide emergency respite care program

Maryland's Respite Care Grant Application: Progress Activities

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- Grant was awarded by ACL in August 2016
- Developed model for 4 working committees to assist in accomplishing project mission
 - ▣ Training, Volunteer Development, Access, and Outreach and Expansion
 - ▣ 2 committees have already convened and have held several meetings
- Met with committed partners to present committee concept and recruit participation in October 2016
- Completed procurement process for establishment of Emergency Respite Care Program, public announcement to partners August 2017
- MD Respite Care Coalition reconvened in April 2017 and is recruiting members
- DHS is in the process of getting Project Coordinator position approved

For More Information

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Lifespan Respite Technical Assistance Center



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