Diverse Partnerships to Advance Lifespan Respite Opportunities for Family Caregivers

HCBS Conference
Baltimore, MD
August 30, 2017
Presenters

Dorinda Adams, MSW, LGSW
Programs Manager, Office of Adult Services
Social Services Administration
Maryland Department of Human Services

Jennifer Eastman, MBA
Director of Community Living Policy
Maryland Department of Disabilities

Jill Kagan, MPH
Director
ARCH National Respite Network and Resource Center
Overview

- 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.

- 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:
2) Rising Demand for Long-Term Services and Supports for Elderly People, CBO, June 2013
Effects of Family Caregiving

- 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…

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 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!
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

- 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…..

**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

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 12 New States
2010 12 New States
2011 6 New States
2012 1 New State
2013 1 New State
2014 1 New State
2015 1 New State
2016 2 New States

2012 & 2013 Integration & Sustainability
2014 Long-Term Sustainability
2016 Expansion Supplement

Courtesy of Administration for Community Living
Evolving Focus of Grantee Activities

1. Building a Statewide Infrastructure
2. Service Delivery
3. Systems Integration and Long-Term Sustainability
Lifespan Respite Built on Collaboration

State Lead Agency + ADRC + State Respite Coalition = State Lifespan Respite System
Maryland’s Strategies for Addressing Lifespan Respite Care and Family Caregiver Supports

- 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

- Challenges and bumps along the way
- Successes
- Today’s landscape
Maryland’s 2016 Respite Care Grant Proposal: A Collaborative Effort

- 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

Department of Human Services + Maryland Access Point (MAP) + Maryland Caregiver Support Coordinating Council* = Maryland Respite Care Program

*Until the Maryland Respite Care Coalition can reconvene
Maryland’s Respite Care Grant Proposal: Ambitious Interventions

- 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

- 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

Jill Kagan
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 was supported, in part by grant number 90LT0002, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.