Lifespan Respite: Ensuring Access to Respite Services for all Caregivers

2010 AoA, CMS, and VA National Grantee Meeting
Changing Systems, Changing Lives

Presented by:
Greg Link, U.S. Administration on Aging
Jill Kagan, ARCH National Respite Coalition

Presenters

Greg Link, MA
- Aging Services Program Specialist
- U.S. Administration on Aging

Jill Kagan, MPH
- Chair
- National Respite Coalition

Session Overview

- Caregiving in the U.S.
- What is Respite/Lifespan Respite?
- State Models for Lifespan Respite
- Road to Federal Legislation
- Federal Program Implementation
- Getting Involved
- Q&A/Discussion

Caregiving in the U.S.

- More than 50 million family caregivers provide 80% of long-term care in the US.
- Valued at over $375 billion a year in uncompensated care, more than was spent on Medicaid in 2007.

Caregiving in the U.S.

- Caregivers….
  - Assist relatives and other loved ones
  - Simple to complex tasks
  - Are found in every community
  - Come from every walk of life

Caregiving in the U.S.

- Typical Caregiver is
  - 48 years old
  - Female
  - Employed outside the home
  - Caring for mom*
- However…..

***Source**: *Caregiving in the U.S. 2009.* Bethesda, MD: National Alliance for Caregiving and Washington, D.C.: AARP, 2009.

Caregiving in the U.S.

- Caregivers are….
  - Often “sandwiched” between two generations
  - Grandparents or other relatives
  - Families of military personnel
  - Care for adults over age 18 with special needs

What is Respite?

- Foundation of Caregiver Support
  - Temporary Relief for Caregivers
  - Strengthens Family Systems
  - Protects Health and Wellbeing
- Defined by the Lifespan Respite Care Act as…

  ”planned or emergency care provided to a child or adult with a special need in order to provide temporary relief to the family caregiver of that adult or child.”

The Lifespan Respite Approach

- Not a New Concept
- Community-Based Partnerships
- Diverse Program Structures and Operation
- Varying Levels of Development/Support

Building Blocks for Lifespan Respite

- Medicaid Waivers and Medicaid Deficit Reduction Act Amendments of 05
- National Family Caregiver Support Program
- Block Grants (Maternal and Child Health, Social Services, Children's Mental Health)
- Federal Categorical Funding Streams, such as CAPTA, ADD Family Support, Alzheimer's Demos
- IDEA, Part C
- State Respite or Family Caregiver Support Programs

Characteristics of State Lifespan Respite Programs

- Identify and coordinate existing respite resources;
- Identify service gaps and create and monitor new respite services;
- Recruit, train, and pool paid and volunteer respite providers;

Characteristics of State Lifespan Respite Programs (con't)

- Provide public awareness information; and
- Connect families with respite payment resources, providers, and training to promote consumer direction.

State Models for Lifespan Respite

Oregon's Lifespan Program: Structure

- In 1997, Oregon Department of Human Services (DHS) charged by state law to develop statewide respite coordination.
- DHS works directly with 22 local networks serving all 36 counties. State contracts with AAA's, Mental Health programs, other community-based organizations to run a local network.
- State Advisory Board

Nebraska's Lifespan Program: Structure

- Modeled on Oregon Lifespan Respite Program, the *Nebraska* Respite Network created by legislation in 1999
- Implemented by Nebraska Health & Human Services System (HHSS)
- HHSS contracts with six regional entities to form the Lifespan Network.

Nebraska's Lifespan Program: Services

- Six Regional Entities Responsible for:
  - I & R– match family to provider
  - Provider Recruitment (over 1500)
  - Training of providers and consumers
  - Quality assurance and program evaluation
  - Public awareness
  - Lifespan Respite Subsidy program serves families up to 312% of poverty

Oklahoma's Lifespan Program: Structure

- *Oklahoma Respite Resource Network:* Statewide partnership of public and private agencies with respite funding of over $1.4 million
- Partnering State Agencies: Developmental Disabilities, Mental Health, Aging, Maternal and Child Health, others
- No local/regional structure

Oklahoma's Lifespan Program: Vouchers and Consumer Direction

- Dept of Human Resources manages voucher program
- Families entitled to up to $400 in vouchers/ 3 months; Income eligibility $60,000 annually
- Encouraged to consider family, friends or coworkers, civic organizations, churches to provide respite

Oklahoma's Lifespan Program: No Local/Regional Structure

- ORRN relies on already existing statewide resource and referral system (OASIS) through an 800 toll-free number to link families to the program, to respite services and to training opportunities.

Wisconsin's Lifespan Program: Structure

- Created by statute in 1999, State Department of Health and Family Services (DHFS) contracts with private, nonprofit Respite Care Association of WI, to run the program.
- Five regional lifespan networks (one in each of the five DHFS regions) serve seven counties.

Wisconsin's Lifespan Program: Services

- Statewide information and referral, technical assistance, and training
- Local linkage to existing programs and funding
- Local gap funding
- Local provider recruitment and training
- Advocacy

Wisconsin Lifespan Program: Differs from the Others

- Program run out of private state respite coalition, rather than state agency
- Not statewide – only nine counties currently served

Roles of State Respite Coalitions in Existing Lifespan Respite States

- ***Wisconsin***: Respite Care Association of Wisconsin (RCAW) advocated for enactment of state Lifespan Respite legislation in 1999; Became lead agency for implementing state's Lifespan Respite program
- ***Nebraska****:* Nebraska Respite Coalition advocated for enactment of state Lifespan Respite legislation; continues as an all volunteer-run nonprofit private advocacy entity.
- ***Oklahoma***: State agency task force that now meets regularly to monitor and improve the program

The Road to Federal Legislation

- Lifespan Respite Care Act of 2006
  - Advocacy
  - Signed on December 21, 2006
  - Based on Model State Programs
  - Establishes Respite as a National Priority

Lifespan Respite Care Program Objectives

- Enhance and Expand Respite Services
- Improve Coordination and Dissemination
- Improve Access
- Fill Service Gaps
- Improve Overall Service Quality

The Lifespan Respite Care Act

- Provides for Mandatory Activities:
  - Development or Enhancement of State and Local Lifespan Respite Systems
  - Provision of Planned or Emergency Respite for All Ages
  - Volunteer/Provider Recruitment & Training
  - Information to Caregivers
  - Access Assistance

Lifespan Respite Programs Must…

- Advance State's Ability to Meet Respite Needs
- Serve all Population/Disability Groups
- Coordinate With, and on Behalf of, Existing Respite Programs and Infrastructures
- Have a Consumer Focus
- Demonstrate Stakeholder Collaboration

Who is Eligible for Lifespan Respite?

Family members of any age, foster parents or other adults (18+) providing unpaid care to:

- Adults and children of all ages with all disabling and chronic conditions

Program Implementation

- Authorized in 2006
- Funded in 2009 and 2010 at $2.5 Million
- Competitive Bidding Process
  - 12 States funded in FY09
  - Up to $200,000 for three year projects
  - TA Activities

Program Implementation

- Eligible Entities
  - State Units on Aging
  - State Medicaid Agencies
  - Other State Agencies

In concert with…

- Aging and Disability Resource Centers
- State Lifespan Respite Coalition

FY 2009 Lifespan Respite Care Program State Grantees

- Alabama
- Arizona
- Connecticut
- District of Columbia
- Illinois
- Nevada
- New Hampshire
- North Carolina
- Rhode Island
- South Carolina
- Tennessee
- Texas

For more information about the Lifespan Respite Care Program and the FY 2009 Grantees, see
http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx

FY 2009 Grantee Activities

- Identification & centralization of all respite and caregiver training resources in the state
- Coordination of emergency respite with APS
- Connect the Coalition to the work of ADRCs and AAAs
- Creation of a statewide 800-respite number
- Create a "Respite Care Network" as an information portal
- Modify existing direct support training models for use with respite providers
- Creation of a statewide "Respite Coordination Center"

Role of State Respite Coalitions

- State Respite Coalition Activities: Advocacy, Networking, Provider Recruitment and Training, I&R, Fundraising, Voucher Programs
- Role in New Programs: Main portal for respite referrals; building respite data bases; helping establish State Task Forces or Advisory Groups

Role of ADRCs

- Outreach
- Respite information clearinghouse and dissemination
- Caregiver training
- Respite hotline
- Advisory role
- Program Administration

Getting Involved

- Prepare for Funding and Application Writing
  - Develop relationships, enhance collaborations with Coalitions, Governor's office, State Agencies
  - Research and Identify Current State Respite Needs/Barriers/Funding Sources
  - Collaborate to Design Your State's Program – What should it look like??

Supporting Documents & TA

- For a copy of the Lifespan Respite Care Act Public Law 109-442, see http://www.archrespite.org/PublicLaw.pdf
- For a copy of the House Energy and Commerce Committee Report on the bill, see http://www.archrespite.org/PublicLawHouseReport.pdf
- ARCH Lifespan Respite Training and TA, see http://chtop.org/ARCH/Lifespan-T/TA.html

Questions?

Contact Us:

Greg Link, MA
Aging Services Program Specialist
U.S. Administration on Aging
Washington, DC
Greg.link@aoa.hhs.gov

Jill Kagan, MPH
Program Director
ARCH National Respite Network and Resource Center
Lifespan Respite Training and TA Center
Annandale, VA
jbkagan@verizon.net