
Updated 2017
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
Value of Family Caregiving

- The estimated economic value of their unpaid contributions is approximately $470 billion annually (AARP Public Policy Institute, 2015).
- Informal caregiving in the U.S. by friends and relatives of the aging is valued at $522 billion a year (Rand Corporation, 2014).
Family Caregiving is Lifespan!

Majority of family caregivers caring for someone ages 18-75 (53%).

- 39% of family caregivers care for someone ages 50-74.
- 14% care for someone ages 18-49.
- An additional 14.6 million children have complex service needs.

Family Caregiving in [Your State]


- The value of their caregiving is estimated at almost [$XX] billion annually.

- They cannot do it alone!

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 difficulty and role-related effects *(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 can enhance physical and emotional health and quality of life;
- 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 do not receive respite (2015 *Caregiving in the US, NAC/AARP*).

Of those who do, they often receive too little, too late.
Barriers to Respite
Barriers to Respite

- Limited federal and state fiscal resources
- Cost
- Shortage of qualified providers
- Limited respite options or appropriate programs
- Reluctance to use respite or self-identify as caregiver
- Access issues
  - Multiple funding streams with confusing and restrictive eligibility
  - Lack of information
Bureaucratic Maze of Funding Streams and Services

- Medicaid Waivers
- Veterans Respite
- National Family Caregiver Support Program
- Block Grants (TANF, Maternal and Child Health, Social Services, Children’s Mental Health)
- Federal Categorical Funding Streams, such as CAPTA, Family Support, Alzheimer’s Demos
- State Respite or Family Caregiver Support Programs
What is Lifespan Respite?
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.

- Original Lifespan Respite Programs for Best Practice: OR, OK, WI, and NE designed to improve respite access
Lifespan Respite is like a Quilt

- It weaves together extremely important, but fragmented funding streams, disparate and duplicative programs, and silos to form a seamless system that make barriers invisible to families.
Characteristics of Lifespan Respite Programs

- 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
Moving from Barriers to Building Blocks

By coordinating siloed funding and service streams, Lifespan Respite converts barriers to building blocks for accessible respite systems for all.
First State Lifespan Respite Programs
Oregon’s Lifespan Program

- **State Agency**: In 1997, Oregon Department of Human Services (DHS) charged by state law to develop statewide respite coordination.

- **Relied on Local Systems to Build Resources**: DHS worked directly with 22 local respite networks (LRNs) serving all 36 counties in Oregon.

- **Diverse State Advisory Council brought Lifespan perspective**.

Note: Despite the fact that the Oregon Lifespan Respite Program was unfunded in 2010 because of serious state budget constraints, the program is included because it serves as a unique model for Lifespan Respite coordination that successfully demonstrated improved access to respite for over 14 years.
Nebraska’s Lifespan Program

- *Nebraska* Lifespan Respite Services Program created by legislation in 1999
  - NE Lifespan Respite Network
  - Lifespan Respite Subsidy (respite payments up to 312% of poverty for families who do not qualify for any existing funding stream)

- *State Agency*: Implemented by Nebraska Department of Health & Human Services
Regional Structure: HHSS contracts with six (6) regional entities to form the NE Lifespan Network
Oklahoma’s Lifespan Program

- **Oklahoma Respite Resource Network (ORRN)** was a statewide partnership of public and private agencies.

- Partnering State Agencies included: developmental disabilities, mental health, aging, maternal and child health and others.

- No local/regional infrastructure.
Oklahoma’s Lifespan Program: Consumer-Directed

- Family Caregivers eligible for respite vouchers of $200-400 every three months as long as funds are available.
- Encouraged to choose own providers from community/family support network.
- Program relies on existing funding streams.
Federal Lifespan Respite Program
Moving to National Scale

- Lifespan Respite law signed in 2006
- Funded for the first time in 2009 at about $2.5 million
- Level funded each year
- In 2016, program received first increase to just under $3.5 million.
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
Current Status

37 States and DC have received Lifespan Respite Grants
State Lead Agency

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

In concert with...

- Aging and Disability Resource Centers
- State Lifespan Respite Coalition
Lifespan Respite Built on Collaboration

State Lead Agency + ADRC + State Respite Coalition = State Lifespan Respite System
Mandated Collaboration: What does it Mean for Your State?

- ADRC and State Respite Coalitions must be a partner in program implementation.
- The State’s Application must include:
  - Memorandum of agreement regarding the joint responsibility for the eligible State agency's Lifespan Respite program between the eligible State agency and a public or private nonprofit statewide respite coalition or organization.
Role of State Agency

- Program Administration and Implementation
- Program Oversight
- Contracts to Local Entities
- Assuring 25% non-federal match
Role of Aging and Disability Resource Center

- Assist with information and referral
- House respite data bases
- Engage in outreach and public awareness
Role of State Respite Coalition

- Many state respite coalitions predate Lifespan Respite; others developed because of it.
- Coalitions have history of advocacy and networking; some progressed to service delivery and training.
- Coalition’s role and responsibilities determined by decisions made jointly between state lead agency and the coalition.
Coalition’s Significance in Lifespan Respite Program

- Brings age and disability diversity
- Brings caregiving and respite expertise and skills
- Ensures ongoing support, cohesion, and sustainability for the program
State Match Requirement

25% State Match can be:

- Cash
- In-Kind
Lifespan Respite Programs Must…

- Advance State’s ability to meet respite needs
- Serve all population/disability groups, especially gap populations
- Coordinate with, and on behalf of, existing respite programs and infrastructures
- Have a consumer focus
- Demonstrate stakeholder collaboration
Evolving Focus of Grantee Activities

- Building a Statewide Infrastructure
- Service Delivery
- Systems Integration and Long-Term Sustainability
Needs Assessments and Environmental Scans

Respite Registries and Centralized Databases

Marketing and Outreach Campaigns

- Give Caregivers a Hand (AZ)
- Respite-It’s OK to need it, it’s OK to want it, and it’s OK to get it! (MT)
- Respite for you = better care for your loved one (CO)
Service Innovations & Promising Practices

- Consumer-Directed Respite Vouchers
- Volunteer Respite
  - Faith Based initiatives
  - University Students
  - TimeBanks
  - Senior Companions
- Mini-Grant Programs
  - NC’s Just One More Campaign
Service Innovations & Promising Practices

- Emergency Respite
- Rural Respite Models
  - OK’s Mobile Respite
- Respite Provider Training and Recruitment
  - NH Partnership with College of Direct Support
  - WI’s partnership with Easter Seals
State Respite Coalition Examples in Grantee States

- **South Carolina Respite Coalition:**
  - Co-facilitate State Advisory Committee
  - Pull together information on funding streams, respite barriers, identifying respite gaps, voucher administration.

- **North Carolina Respite Care Coalition:**
  - Serve on State Advisory Board
  - Responsible for program material development (e.g. cultural diversity, volunteer respite guide), and voucher admin.
State Respite Coalition Examples in Grantee States

- **Delaware Respite Network**
  - Runs statewide voucher program
  - Holds annual state summit with focus on family caregivers

- **Arizona Caregiver Coalition**
  - Advocacy role: responsible for helping enact state Lifespan respite legislation
  - Coalition volunteers run caregiver helpline
State Respite Coalition Examples in Grantee States

- **New York State Caregiving and Respite Coalition**
  - Holds annual Caregiver Summit
  - NYSCRC website houses program resources
  - Administers mini grants and training
  - Liaison between grantee and community
Lessons Learned

- 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
Sustainability Strategies

- Forging State agency fiscal partnerships
- Integrating respite into LTSS and other State Systems
- Outreach/inclusion of employers
- Strengthening coalitions/securing grassroots support
- Documenting outcomes
- Strategic and long-term sustainability planning
- Identifying natural supports and inclusive community activities for respite
Questions to Consider
How do we build or strengthen our State Respite Coalition? What role will it play?

- Advocacy/Program Sustainability
- Conduct Program Oversight
- Provide Guidance and Expertise
- Serve as Respite “Portal” to Lifespan System
- Respite Provider Recruitment/Training
- Develop Products
- Deliver Services
- Facilitate Networking
What will be the role of the ADRC?

- Outreach, public awareness and information dissemination
- Serve on State Advisory Teams or Task Forces
- Expand caregiver training
- Embed respite hotlines or respite registries
What are the short and long term goals we need to reach to become a Lifespan Respite state?

- Develop a timeline to prepare for funding and application writing
- Develop relationships, enhance collaborations between ADRCs, Respite Coalition, Governor’s office, State and local agencies
- Research and identify current State respite needs/strengths/barriers/funding sources
- Collaborate to design State program – What should it look like?? How will we measure success?
- Develop sustainability plan!!
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ARCH National Respite Network and Resource Center
http://www.archrespite.org/

Lifespan Respite
Technical Assistance Center

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