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 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)
Caregiving is across the Lifespan

A majority of family caregivers care for someone between 18 - 75 years of age (53%).

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

Caregiving in South Dakota

- In 2013, more than 84,600 caregivers provided 79 million hours of care.
- The value of their caregiving is estimated at almost $1,030 million annually.
- They cannot do it alone!

Effects of 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 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

- Lack of qualified respite providers
- Reluctance to use respite or self-identify as caregiver
- Rural nature of the state
- Access issues
  - Lack of awareness
  - Multiple funding streams with different eligibility criteria
Bureaucratic Maze of Funding Streams and Services

- Various Medicaid Waivers
- Veterans Administration Respite
- National Family Caregiver Support Program
- State Respite Programs
- Family 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.
Lifespan Respite is like a Quilt

- It weaves together extremely important, but fragmented funding streams, different and duplicative programs, 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 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 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 charged by state law to develop statewide respite coordination.

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

- Diverse State Advisory Council brought Lifespan perspective.
Nebraska’s Lifespan Program

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

- 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** 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

- 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

Administration for Community Living administers competitive state grants for mandatory use 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
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
2017  2 New States

2012 & 2013 Integration & Sustainability
2014 Long-Term Sustainability
2016 Expansion Supplement
2017 Advancing Lifespan Respite Systems

Courtesy of Administration For Community Living
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?

- 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
- Provide a 25% non-federal match
Role of Aging and Disability Resource Center

- Information and referral
- Gather data
- Engage in outreach, public awareness and information dissemination
Role of State Respite Coalition

- Many state Respite Coalitions predate Lifespan Respite.
- Coalitions have a history of advocacy and networking; some progressed to service delivery and training.
- Coalition’s role and responsibilities determined by decisions made jointly between state 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
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
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
- Respite Provider Recruitment/Training
- Develop Products
- Promote Access to Services
- Facilitate Networking
What are the short and long term goals we need to reach to become a Lifespan Respite state?

- Develop and enhance collaboration between ADRC, Respite Coalition, Governor’s office, Legislature, state and local agencies
- Research and identify current state respite needs, strengths, barriers, funding
- Collaborate to design state program – What should it look like? How will we measure success?
- Develop sustainability plan
ARCH Resources and Tools

- Fact Sheets, Guidebooks and Manuals
- Webinars
- Conference Calls
- Phone/Email Technical Assistance
- Lifespan Respite Exchange
- ARCH Quick News Updates
- National Respite Locator Service
Lifespan Respite
Technical Assistance Center

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