Presentation Overview

- Family Caregiving in the U.S.
- Respite Definition, Benefits, Access, Funding, Barriers
- Lifespan Respite Care Program Role in Promoting Collaboration and Coordination to Improve Access
- Lifespan Respite Program Requirements
- Lifespan Respite Federal Administration and Funding
- Eligible entities, match requirement
- Partner Roles
- Lifespan Respite Grantee Activities
- Lessons Learned
- Questions to Consider
Family Caregiving in the U.S.

- 53 million adults in the U.S. are family caregivers of an adult or a child with a disability or chronic condition.

- The estimated economic value of their unpaid contributions is approximately $600 billion annually,

- 80% of those needing long-term services and supports live at home.

Family Caregiving is Lifespan!

- Majority of family caregivers caring for an adult ages 18-75 (54%).
- 40% of family caregivers care for someone ages 50-74;
- 14% care for someone ages 18-49;
- 1 in 5 households in the U.S. cares for a child with special healthcare needs (CSHCN), representing nearly 14 million children.

Effects of Family Caregiving

- Many caregivers derive spiritual, emotional and even physical benefits. For others – high stress leads to poor health, emotional difficulties and financial strain.

- Nearly 1 out of 4 caregivers feel caregiving has made their health worse; 1 in 5 report high physical strain as a result of caregiving duties; and 4 in 10 caregivers consider their caregiving situation to be highly stressful (National Alliance for Caregiving, 2020).

- 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
Everyone Needs Respite!

- Reduces Stress
- Improves physical and emotional health
- Enhances relationships and reduces social isolation
- Care recipients benefit, too!
Yet, 86% of family caregivers of adults do not use respite.

A significant percentage of caregivers of CSHCN with an unmet need do not receive respite (63% to 75%).

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

- 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

- Medicaid Waivers
- Family Caregiver Support Program
- Veterans Caregiver Support Program
- Other Federal Programs
- State Funded Respite Programs
- Private Sector Options
Lifespan Respite Care Program

Definition: Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.
Lifespan Respite Care Program

Like a quilt, it weaves together important, but fragmented funding streams, disparate and duplicative programs, and eligibility silos to form a seamless system.
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.
Moving to a National Scale

- Lifespan Respite signed into law in 2006
- Funded for the first time in 2009 at about $2.5 million and stayed at this level until 2016
- Incremental increases to reach $10 million in FY 2023
- Since 2009, 38 states and DC have received at least one Lifespan Respite Care Program grant
Federal Administration

US Administration for Community Living administers competitive state grants for these required 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 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
Eligible State Lead Entities

- State Agency that administers the Older Americans Act
- State Medicaid Agency
- Another State Agency appointed by the Governor

In concert with...

- Aging and Disability Resource Center/No Wrong Door System
- State Lifespan Respite Coalition
State Match Requirement
25% State Match can be:

CASH

IN-KIND
Lifespan Respite Systems Built on Collaboration

State Lead Agency + ADRC/No Wrong Door + State Respite Coalition → State Lifespan Respite System
Mandated Collaboration: What does it Mean for Your State?

- ADRC/No Wrong Door and State Respite Coalition must be a partner in program implementation.

- The State’s grant 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 Lead Agency

- Program Administration and Implementation
- Program Oversight
- Contracts to Local Entities
- Assuring 25% non-federal match
What will be the role of the ADRC?

- Outreach, public awareness and information dissemination
- Information and referral; Options counseling for respite
- Serve on State Advisory Teams or Task Forces
- Expand caregiver training
- Embed respite hotlines or respite registries
Coalition’s Significance to Lifespan Respite Program

- Brings age and disability diversity
- Brings Caregiving and Respite expertise and skills
- Ensures ongoing support, cohesion, and sustainability for the program
Evolving Focus of Grantee Activities

- Building a Statewide Infrastructure
- Service Delivery
- Systems Integration and Long-Term Sustainability
Lifespan Respite Grant Activities

Systems Building
Connecting families to respite

Capacity Building

Service Innovations

Sustainability Strategies
Systems Building

- Establishing no wrong door to respite
- Respite registries, centralized databases, websites
- Cross-agency collaboration
- State Coalition building/Regional hubs
- Marketing and outreach campaigns
Service Innovations

- Self-directed respite vouchers
- Volunteer and faith-based respite
- Emergency/crisis respite
- Rural respite models
- Respite for Kinship Families
- Sibshops
- Culturally and linguistically competent respite services
Respite provider recruitment, training and retention

Minigrants to community and faith-based organizations for new programs and services

Identification and promotion of informal or alternative respite options (especially during the pandemic)

Students as respite providers
Sustainability Strategies

- Integrating respite into No Wrong Door, LTSS State Systems
- Engaging innovative fiscal strategies
- Forging State agency fiscal partnerships
- Outreach/inclusion of employers
- Strengthening Coalitions/Expanding Collaborator Diversity/Securing grassroots support
- Expanding reach of informal services and community supports
- Documenting outcomes
- Strategic and long-term sustainability planning
State Highlights

- State Summaries of Lifespan Respite Grant Activities
  archrespite.org/lifespan-programs/state-lifespan-respite-grantee-activities

- In Support of Family Caregivers: Key Accomplishments of Lifespan Respite Grantees
  archrespite.org/library/key-accomplishments-of-lifespan-respite-program-grantees
Lessons Learned

- It takes time....
- Build on model approaches
- Partnerships are essential
- Flexibility is key
- Performance measurement from day one
- Sustainability planning and focus are critical from the outset
Supporting Documents

- Lifespan Respite Care Act
  Public Law 109-442


- Past Lifespan Respite Care Program Notice of Funding Opportunities (NOFOs)
  archrespite.org/ta-center-for-respite/lifespan-respite-101/#FOAs
Questions to Consider
What role will the State Respite Coalition 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/No Wrong Door?

- Outreach, public awareness and information dissemination
- Information and referral; Options counseling for respite
- 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 achieve a statewide coordinated respite system?

- Develop a timeline to prepare for funding and application writing
- Identify and develop relationships, enhance collaborations between ADRCs, Respite Coalition, Governor’s office, State and local agencies
- Grow the coalition - Identify and engage stakeholders from businesses, disability and aging organizations and advocates, faith-communities, state policy makers, health care providers, provider agencies, leaders from diverse communities.
- Research and identify current strengths, barriers, funding sources
- Assess family caregiver respite needs and service gaps statewide.
- Collaborate to design State program – What should it look like?? How will we measure success?
- Develop sustainability plan!!
For More Information

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