



Leveraging Lifespan Respite to Build and Sustain Respite Services for Family Caregivers

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Overview

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- National picture of family caregiving in the U.S.
- What is respite?
- Why is it important to family caregivers?
- Barriers and challenges to accessing services
- Role of Lifespan Respite Care Program
- Sustainability Strategies: Lessons Learned
- State Examples: NC and DC

Family Caregiving in the U.S.

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- 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: 1) National Alliance for Caregiving and AARP Public Policy Institute. *Caregiving in the U.S. 2015*;
2) Congressional Budget Office (2013). *Rising Demand for Long-Term Services and Supports for Elderly People*.

Effects of Family Caregiving

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- 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*).

Sources: 1) Population Reference Bureau (2016). Family Caregiving. *Today's Research on Aging*. Issue 33; 2) National Alliance for Caregiving and AARP Public Policy Institute. *Caregiving in the U.S. 2015*; 3) Wolff, J.L. PhD, et al. (2016). A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities. *JAMA Intern Med.*, Pub online February 15

Respite is...

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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

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- ❑ Improves family caregiver stress levels, which can enhance physical and emotional health;
- ❑ Improves overall family well-being, family relationships and stability;
- ❑ Reduces hospital costs and may help avoid or delay more costly foster care, nursing home or other out-of-home placements.

Respite: Too Little, Too Late

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- 85% of family caregivers of adults do not receive respite (*2015 Caregiving in the US, NAC/AARP*).
- Of the 44% of family caregivers who were providing substantial help with health care, fewer than 17% use respite (*Wolff, National Study of Caregiving, 2016*).
- Of those who receive respite, they often receive too little, too late.



Barriers to Respite

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- Limited Resources
- Cost
- Shortage of qualified providers
- Limited respite options or appropriate programs
- Reluctance to use respite
- Access issues
 - ▣ Confusing and restrictive eligibility issues
 - ▣ Lack of information

Lifespan Respite...not just care or a service

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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

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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 Built on Collaboration

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Evolving Focus of Grantee Activities

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Sustainability First Step: Possible Funding Streams

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- ❑ Medicaid Waivers, Demos or HCBS State Plan Amendments
- ❑ Veterans Services
- ❑ National Family Caregiver Support Program
- ❑ Social Services Block Grant
- ❑ State Respite, Family Support or Caregiver Support Programs

Source: ARCH National Respite Network and Resource Center (2015). *Federal Funding and Support Opportunities for Respite: Building Blocks for Lifespan Respite Systems*. http://www.lifespanrespite.memberlodge.org/Federal_Funding_Guide

Sustainability Strategies

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- ❑ Forging State agency fiscal partnerships
- ❑ Integrating respite into LTSS and other State Initiatives
- ❑ Outreach/inclusion of employers
- ❑ Securing grassroots support
- ❑ Strengthening Coalitions
- ❑ Strategic and Long-term Sustainability Planning
- ❑ Natural Supports and Inclusive Community Activities

For More Information

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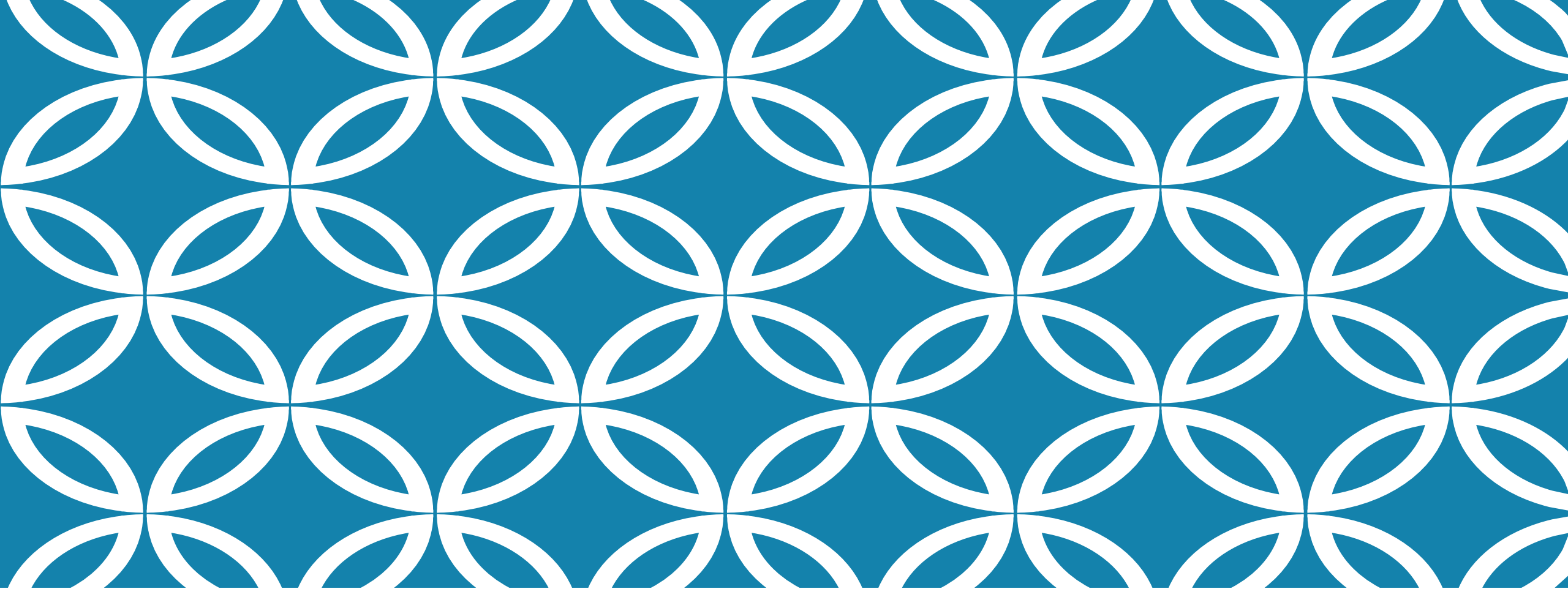
ARCH National Respite Network
and Resource Center

<http://www.archrespite.org>

Lifespan Respite Technical Assistance Center



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LEVERAGING & SUSTAINING LIFESPAN RESPITE IN NORTH CAROLINA

*HCBS CONFERENCE
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NORTH CAROLINA'S LIFESPAN RESPITE GRANTS

- 2009 Lifespan Respite Care Grant
– Initial Funding to States
- 2011 Expansion Supplement Programs
- 2012 Building Integrated & Sustainable Programs
- 2014 Building Long-term Sustainability in State Programs



Our Work to Date has Focused On:

- Assessing the respite landscape
- Uncovering service gaps
- Increasing awareness & effective use of respite
- Paying for direct respite services
- Partnerships to encourage/examine new service models and enhancements
- Understanding and impacting where caregivers intersect with services
- Seeking to embed a caregiver view in those intersections/interactions
- Building capacity of our state's Respite Care Coalition

DIRECT SERVICE

To date, this project has awarded more than \$240,000 to respite providers and the North Carolina Respite Care Coalition for family caregiver respite vouchers and enhanced services!



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A FEW HIGHLIGHTS FROM THE PREVIOUS GRANTS

- 2009 Lifespan Respite Care Grant
 - Initial study of respite landscape, gaps and barriers to access
 - Funded NCRCC to produce “Lifespan Respite – An Information Guide for Developing, Recruiting, Training and Retaining Volunteers”
- 2011 Expansion Supplement Programs
 - Funded nine mini-grants to providers of respite to expand services
 - Initial development & funding of the NCRCC Respite Voucher Program
 - Maximizing Use of Respite Planning Tool
- 2012 Building Integrated & Sustainable Programs
 - Developed on-demand, web-based training, **“Planning and Using Respite: Working with Family Caregivers across the Lifespan.”**
 - Funded NCRCC staff member, website redesign, board travel, and marketing materials

MAXIMIZING RESPITE PLANNING TOOL

Basis of project stemmed from earlier research done by Dale A. Lund and colleagues at California State University at San Bernardino and the University of Utah. Findings supported that:

- Respite use does not automatically translate to lower burden/less stress for caregivers
- One study showed 46% of caregivers reported being only somewhat or not satisfied with how they spent their respite time
- Studies showed when a caregiver uses their respite time to do what they intended to do, he/she may feel less burden and more satisfaction with their caregiving role

WHY TRY TO IMPACT WHAT CAREGIVERS DO WITH THEIR RESPITE TIME?

Next to payment for family caregiver duties (which is not provided), respite is most requested service in NC for caregivers of older adults and persons with dementia

Average respite voucher/service awarded from OAA funds ranges from \$500 to \$2000 per year, per family

With flat funding, we looked at how to enhance the value of what we could provide family caregivers

SETTING GOALS TO MAXIMIZE YOUR RESPITE TIME

“On this sheet of paper, please write down one to three specific goals of what you would like to accomplish during your respite time this week/month. Your goals can be anything (e.g., sleeping, cleaning, going to lunch with a friend), but they must be attainable during the respite time that is available to you. We recommend that you choose activities that:

you have always enjoyed doing;

you did before you became a caregiver but may not have been doing lately;

have religious or spiritual meaning to you;

may improve satisfaction with caregiving;

may reduce the stress you might feel from caregiving;

may increase your respite time;

encourage you to use your respite more regularly.”

Goals:

EFFECT OF RESPITE PLANNING ON CAREGIVER BURDEN SCORES

A Repeated Measures ANOVA was conducted to examine whether or not the provider discussing respite planning with the caregiver had an effect on the caregiver burden scores. An effect was found such that average caregiver burden scores significantly declined from pre- to post-respite only for those caregivers that talked to their provider about respite planning.

Burden scores did decline for those caregivers that did not receive consultation from their provider on respite planning, but the decline was not significant.

PLANNING AND USING RESPITE: WORKING WITH FAMILY CAREGIVERS ACROSS THE LIFESPAN

Online, on-demand modules

Designed for human service workers who interact with family caregivers but not as a primary function of their job

Still available without charge in NC.
Continuing to promote them

The training is comprised of the following modules:

Introduction: Caregivers, Caregiving and Respite

Engagement and Screening

Assessing Caregivers

Planning Principles and Tools

Planning Examples and Following Up

CURRENT WORK WITH 2014-2017 FUNDING

* **State Strategic Plan for Respite 2015-2020 Recommendations**

- Create a sustainable, collaborative Lifespan Respite organizational structure
- Secure ongoing staffing for the North Carolina Respite Care Coalition (NCRCC)
- Develop and implement an awareness and advocacy agenda
- Diversify funding for the NCRCC and respite vouchers, using Lifespan Respite Program Grant funds as a base
- Work with key state agencies to systematically analyze and improve respite policies and processes.

PARTNERSHIP WITH MONEY FOLLOWS THE PERSON

- Managed \$150,000 in MFP Rebalancing dollars awarded to Caregiver Peer to Peer Mentor Projects. Projects concluded.
- Current \$100,000 partnership is about care management and developing and implementing care planning tools with a caregiver focus. Funding also includes respite vouchers.

Money Follows the Person (MFP)

The Money Follows the Person (MFP) Rebalancing Demonstration Grant helps states rebalance their Medicaid long-term care systems. There are currently forty-three states and the District of Columbia participating in the demonstration.

CONNECTION BETWEEN MFP, CAREGIVERS, AND LIFESPAN RESPITE

- * Literature strongly supports the value of assessing the needs of family caregivers and addressing those needs in the plan of care. If family caregivers are not connected to needed services and supports, their own health and well-being may be compromised, increasing the risk that they will not be able to continue to provide care in the community.
- * ***Ultimately, we hope to help family caregivers continue to provide care for their family members who are at risk for facility placement.***
- * We will also examine the role of respite and a caregiver's intent to pursue facility-based placement for their family member.

LEVERAGING & SUSTAINING LIFESPAN RESPITE IN NC IS ABOUT...

- Enhancing what respite can do for families and building a village of supporters to share this message
- Seeking supporters from those who benefit from reaching and impacting family caregivers
- Building the capacity of those who support your mission & purpose
- Inviting and enlarging the table of stakeholders continuously
- Being clear about where you see connections even if it is not on their radar yet
- Applauding other's efforts and helping them grow

District of Columbia Office on Aging
Aging Disability Resource Center
Lifespan Respite Program

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District of Columbia

Lifespan Respite

- District of Columbia Office on Aging/ Aging Disability Resource Center (DCOA/ ADRC) received Lifespan Respite grants in years 2009, 2011, and 2013.
- Grant Objectives Met:
 - Established a respite coalition,
 - Improved coordination and dissemination of service delivery between different programs that optimize family caregiver support, and
 - Included Lifespan Respite in State Plan.

Lifespan Respite Coalition

- DCOA/ADRC established the coalition in September 2010.
- The coalition accomplished major activities such as:
 - Developing governance documents.
 - Creating a brochure and factsheet
 - Conducting focus groups
 - Establishing relationships with government and non-profit organizations.
- One coalition goal was to transfer the coalition to a non-government agency to sustain the program after the grant was completed.

Transferring the Coalition

- In 2016 DCOA/ADRC transferred the respite coalition to the Kadamba Tree Foundation.
- The Kadamba Tree Foundation is a nonprofit organization that supports family caregivers in finding effective ways to thrive through life's challenges.

Leveraging Respite in Long Term Care and Support

- DCOA/ADRC has working relationship with DC State Medicaid Agency Department of Health Care Finance.
- We assist caregivers to access the Elderly and Persons with Disability Waiver .
- One of the services under the Waiver is respite for 480 hours a year in addition to in-home support.

Questions

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