IT ALL STARTED WITH A GRANT ...

And a whole lot of people behind the scenes for years working to make it all possible

NC Lifespan Respite Planning Summit
June 2015
Why Lifespan Respite?

Caregivers are at Greater Risk of:

- Depression
- Guilt, anger, denial
- Declines in physical health
- Strained social & family relations
- Sleep disorders
- Anxiety about aging
- Neglect of self and others
- Less marital closeness
- Work absenteeism and job loss
- Exhaustion
- Loss of friendships
The **Lifespan** Respite Care Program

- Funding comes from a federal appropriation and awarded through a competitive application process
- Grants managed by the U.S. Administration for Community Living
- Eligible applicants are state units or an organization appointed by the Governor
- Required partners include a state’s respite coalition. Involvement with the ADRC network also required
North Carolina’s Lifespan Respite Grants

• 2009 Lifespan Respite Care Grant

• 2011 Expansion Supplement Programs

• 2012 Building Integrated & Sustainable Programs

• 2014 Building Long-term Sustainability in State Programs
Our Work to Date has Centered Around:

- assessing the respite landscape
- uncovering service gaps
- increasing awareness and effective use of respite
- paying for direct respite services
- Partnering to encourage and test new service models
- Understanding and impacting where caregivers connect with service intersections
- Seeking to embed a caregiver view in those intersections/interactions
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 and enhance respite services
  - Initial development and funding of the NCRCC Respite Voucher Program

- **2012 Building Integrated & Sustainable Programs**
  - Developed on-demand, web-based training entitled, “Planning and Using Respite: Working with Family Caregivers across the Lifespan.”
  - Training still available without charge. Link can be shared directly to anyone interested
  - Funded NCRCC staff member, website redesign, board travel, and marketing materials
In order to raise awareness among service professionals and embed a caregiver & respite focus...

...the North Carolina Lifespan Respite Project created web-based, on-demand training modules entitled,

“Planning and Using Respite: Working with Family Caregivers across the Lifespan.”
A Few Quotes from Training Participants

“User-friendly system with great information”
~ Bridget O’Connell, RN MS, Community Based Manager, Professional Nursing Service

“The respite training program helped me to be a well-informed provider of information and support to caregivers that I work with on a daily basis.”
~ January Brown, Human Services Planner
Eastern Carolina Area Agency on Aging

“This is an excellent tool – well conceived, well researched, and well developed. It will advance the field immeasurably.”
~ Jill Kagan, Program Director, ARCH National Respite Network and Resource Center

“They were fantastic!”
~ Leslie Breen, Senior Center Development Specialist, NC DAAS
Partnership with Money Follows the Person

• Have managed $150,000 in MFP Rebalancing dollars that were awarded to Caregiver Peer to Peer Mentor Projects

• One project concluded, one in final month; One beginning year one

• In planning stage to propose new RFA impacting families in transition or at risk of transition
Direct Service

To date, this project has awarded more than $200,000 to respite providers and NCRCC for family caregiver respite vouchers and enhanced services!
2014 Building Long-term Sustainability in State Programs

- Asked states to choose from a set of options and expand on previous work toward more complete integration and sustainability
  - Strategic state plan for respite
  - Business plan for the NC Respite Care Coalition
  - “Braiding” or “weaving” together of resources where possible
  - Employer/Employed caregiver initiatives
  - Continued partnership with Money Follows the Person and Rebalancing Fund/Transitions initiatives
Partnership Between DAAS and NCRCC

• NC DAAS has had a contract with NCRCC (or a fiscal agent) each year of the grants to complete activities that furthered respite and the Coalition

• Our current grant, 2014 Building Long-term Sustainability in State Programs, is our closest partnership yet.
  • Linda Kendall Fields is sharing her time between NC DAAS Lifespan Respite Grant activities and the NCRCC
  • NC tasked with researching and developing a Statewide Strategic Plan for Respite. This plan will also include a Business Plan for NCRCC
  • Annual funding for the NCRCC Respite Voucher Program
All of this leads us to where we are today
Summit Goals and Learning Objectives

Goal:
• To create a unified and achievable vision for improving family access to quality Lifespan Respite services in North Carolina.

At the end of the Summit, participants will be able to:
  1. Recognize the importance of respite services to families across the lifespan
  2. Describe the Lifespan Respite initiatives underway at a state and national level
  3. Apply new information to the findings of the NC Lifespan Respite Strategic Planning Survey and develop preliminary strategies towards achieving an optimal Lifespan Respite system in North Carolina.
  4. Discuss next steps for further development and implementation of strategies
In short...

We need your expertise, your real world experience, your passion, your respite savvy.

Together, let’s advance what we know and do and seek to reduce barriers to respite use.

Today, we will begin with what you told us in a recent survey
OUR SURVEY:
NORTH CAROLINA LIFESPAN RESPITE STRATEGIC PLANNING STARTS WITH YOU!

March - May 2015
Q1 Please indicate your connection to respite services. Check all that apply.

Answered: 82   Skipped: 0

- I am a family caregiver: 24.39%
- I am a provider of...: 51.22%
- I am a member of the North...: 34.15%
- I serve on the North Carolina...: 15.85%
- I have in the past used (o...: 10.98%
- Other (please specify): 28.05%
Lesson Learned: Beware the Open Ended Question on a Survey to 82 people!
Q2: Imagine that you are designing an optimal Lifespan Respite System in North Carolina that supports family caregivers. List up to 5 characteristics of such a system. (Examples: easy to access; volunteer and paid respite options, etc.)
Answered: 73

1. **Easy to Find/Access** - *61* - Most often cited
2. Variety of Settings - 32
3. Affordable - 29
4. Other Caregiver Support - 22
5. Volunteer Respite Options - 21
6. Flexibility – services/schedule - 20
7. Person/Consumer Directed - 19
8. Paid respite options - 18
9. Well trained/well matched staff - 18
10. Widely Publicized – 16
11. Adequate Funding – 16
12. Person Centered – caring – responsive - 13
13. Policies/practices conducive to service - 10
14. Statewide coverage - 9
15. All Ages and Disabilities - 5
16. Quality –measured – 5
17. Other – e.g., specific populations, ancillary services, comments -12
Question 3

Drawing on your knowledge and experiences, what are the primary challenges to achieving an optimal Lifespan Respite System in North Carolina?

~ 70 respondents

- **Funding limitations – 74 - #1 response**

- **Lack of Awareness - 66 - #2 response**
  - Family awareness
  - Public awareness
  - Legislators/funders

- **Policy/Process/Respite Definitions – 30- #3**
Q4: For Professionals: Please list and comment on any practice, policy and/or procedure you currently have in place that may limit or prevent you from providing respite services effectively.

(See handout with specific policy & practice barriers)
Q5: Steps to Overcome Challenges that Limit and prevent respite? ~ 64 respondents

- More funding – 55
- Advocacy for respite (often cited with funding) – 47
- Public Awareness - 27
- Increase Options/Providers - 26
- Streamline Access – 25
- Clearinghouse for services – 21
- Educate Professionals - 19
- Policy Improvements - 18
- Private/Public Partnerships – 18
Q6: Vision Statement Describing Optimal Lifespan Respite System in NC – 2020 ~ 62 respondents

- Most used words:
Q7 What is your current level of awareness in the North Carolina Respite Care Coalition (NCRCC)?

Answered: 59  Skipped: 23

- Very aware - I am a member... 42.37%
- Somewhat aware - I've... 52.54%
- Not aware - This is the... 5.08%
Q8: Please suggest a few ways that the NCRCC could support a statewide Lifespan Respite System. ~ 41 respondents

- Increase Public Awareness – 32
- Increase Advocacy - 27
- Look for funding options – 25
- Collaborate with partners - 25
Q9: How to Sustain the work of the NCRCC?

~ 46 respondents

- Grants – 32
  - Corporate funding/sponsors – 31
  - Specific funding ideas – 16
  - Admin. $ for respite management – 10
  - Americorps/Volunteer Services – 10
  - Partner with others - 10