



# **It's Not as Easy as it Sounds: Lessons Learned from North Carolina's Caregiver-Directed Respite Voucher Programs**

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## *Presenter Information*

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# *NC FY 2017: The Year of the Respite Voucher*



- NC had unprecedented respite voucher availability.
  - Lifespan Respite Grant-Funded Vouchers → 270
  - Project C.A.R.E Vouchers → 696
    - 588 vouchers funded by legislative appropriation
    - 108 vouchers funded through Money Follows the Person
- Lifespan Respite Vouchers were available to caregivers of individuals of any age with special needs.
- Project C.A.R.E. vouchers were available only to caregivers of individuals with Alzheimer's disease or related dementias.



# *Project C.A.R.E.*

## *Caregiver Alternatives to Running on Empty*

- The only state-funded, dementia-specific support program for individuals who care for loved ones with Alzheimer's disease or related dementias
- Expanded by the NC General Assembly last year:
  - provided funding for respite vouchers
  - doubled the number of Family Consultants from 3 to 6
- Eligible caregivers may receive:
  - education, information, support and care management
  - up to three \$500 respite vouchers each year
- Reimbursement-based voucher program very similar to the Lifespan Respite Voucher Program



# *Opportunity for Evaluation*

- Money Follows the Person also provided funding to the NC Division of Aging and Adult Services to:
  - develop and evaluate the use of new care management tools designed to address the needs of caregivers
  - evaluate the use of respite vouchers to support caregivers in keeping their loved ones at home in the community
- The evaluation focused only on those caregivers providing support for an individual with Alzheimer's disease or related dementia.
- The post-survey process with caregivers has just been completed, and data is now being analyzed with final results due in December.



# *What is Caregiver-Directed Respite?*

Caregiver-directed respite

gives family caregivers

the opportunity to locate, hire, train and pay  
their own providers through the use of vouchers.

Caregivers may hire friends, family or other individuals  
or purchase respite services from agencies.

Options include both in-home and out-of-home respite.



# *NC's History with Caregiver-Directed Respite*

Family Caregiver Support Program



Lifespan Respite



Project C.A.R.E.



# *What Does Caregiver-Directed Lifespan Respite Look Like in North Carolina ?*



- North Carolina's Lifespan Respite Voucher Program offers one \$500 respite voucher per year to eligible caregivers.
- The program is reimbursement-based and is administered through a contract with a fiduciary agent, the High Country Area Agency on Aging.
- During the past year, Lifespan Respite vouchers have been awarded to caregivers of individuals with special needs ranging from 2 to 102 years of age.



# *NC Lifespan Respite Voucher Program Eligibility*

- Caregivers must be at least 18 years old and NC residents.
- Caregivers must be providing unpaid care to someone of any age with special needs.
- Care recipients are generally not eligible for or are not currently receiving other publicly funded in-home or respite care services.
- Priority is given to:
  - those with the greatest economic and social needs
  - those who have not received a break within the previous 6 months
  - families who have no other ongoing in-home assistance



# *Voucher Application Process*

- Caregiver is referred to the program by a professional organization/referring agency.
- Referring agency completes online application on behalf of caregiver.
- Application is processed by High Country Area Agency on Aging (AAA).
- High Country AAA provides approved applicants with:
  - Voucher Award Letter
  - Respite Care Provider Agreement
  - Record of Respite Services
  - “Making Respite Time More Effective” Tool



## *Other Considerations*

Caregiver must be able to:

- Pay for services if bill arrives prior to reimbursement. (Reimbursement check is mailed within 5 business days of receipt of completed paperwork.)
- Screen and hire respite provider.
- Complete required paperwork (Private Provider Agreement, Record of Respite Services).
- Submit required paperwork within 14 days from expiration date noted on award letter.
- Use voucher funds within 90 days (may request 30-day extension).



# *Our Initial Assumptions About Respite Vouchers*

- Most all caregivers awarded a respite voucher would use it.
- Providers would be comfortable working directly with family caregivers.
  - Invoicing
  - Trusting the private pay option
  - Flexibility when the caregiver is “in charge”



# *What We Learned from Experience*

Our assumptions were not correct!

- Between 2014 and 2017, about a third of the funds allocated through respite vouchers were not used.

*AND*

- We received frequent anecdotal reports that some agency providers did not have experience in working directly with family caregivers and were hesitant to do so.



# *Increasing Voucher Use With a Protocol*

- “Making Respite Time More Effective” tool was included in all voucher award packets to help caregivers think about and plan for how they wanted to use their respite time.
- Project C.A.R.E. Family Consultants reviewed this tool with caregivers who received Project C.A.R.E. Vouchers.
- After the vouchers were awarded, follow-up phone calls were made to caregivers to remind them about the voucher, to answer their questions and help them problem-solve any issues with voucher use, at:
  - 30 days
  - 60 days
  - a few weeks before voucher expiration date



# *Preliminary Results*

- We learned that nagging works!
- Approximate utilization rates of allocated respite voucher funding:
  - Lifespan Respite: 85%
  - Project C.A.R.E.: 91%



# *Preliminary Project C.A.R.E. Survey Results*

- 84% of caregivers said that they used their respite plan to do something they enjoyed and felt that the time was well spent.
- 65% responded that it was not at all difficult to locate and hire a respite provider. 31% said it was slightly difficult.
- 88% reported that it was not at all difficult to get reimbursed for respite voucher expenses. 11% indicated it was slightly difficult.
- 95% spent more than \$250 of their \$500 respite voucher.
- 97% reported that they were very or extremely satisfied with the respite services they were able to purchase.
- 92% said the support received through Project C.A.R.E. is playing a role in keeping their care recipient at home and out of a long-term care facility.



## What Caregivers Are Saying

- *“I was so thankful, and I got to pick someone I knew would be honest and trustworthy.”*
- *“This program is my only opportunity for respite. My parents are not comfortable with an agency, so to be able to have someone they know come into the home is invaluable to me.”*
- *“When the program started, I was very stressed, but the Family Consultant encouraged me and kept giving me ideas on how to utilize the program to our benefit. I probably wouldn’t have followed through if it hadn’t been for her.”*



## *What's Trending in NC with Consumer-Directed Respite?*

- Family Caregiver Support Programs in 50 of NC's 100 counties are now offering consumer-directed respite options.
- 61% of Project C.A.R.E. caregivers who responded to the post-survey hired friends, relatives or other individuals to provide their respite care.
  - 17% hired a home care agency or respite service
  - 16% used an adult day care or group respite program
  - 4% used a facility for overnight respite
- 40% of caregivers who received a Lifespan Respite Voucher during the first 6 months of 2017 hired a friend, relative or other individual to provide their respite care.
  - 13% chose adult day care or group respite
  - 3% used a facility for overnight respite



## *An Environment That Supports These Trends Should Include...*

- Registries of individuals who provide private care
- Ongoing, sustainable funding source (no start and stop on availability)
- Caregiver awareness and support
- Education for respite providers
- Enough options in rural areas that caregivers can find respite workers
- A voucher program that is easily used by caregivers regardless of their individual circumstances
- Expansion of number of referring agencies across the aging and disability networks



# *Where We Plan to Go From Here*

- Expand number of referring agencies across the aging and disability networks and increase voucher marketing efforts.
- Partner with NC United Way 2-1-1 system to;
  - train call specialists on respite options
  - expand quantity/quality of respite information in 2-1-1 database
  - train 2-1-1 LTSS Call Specialist on how to complete Lifespan Respite Voucher applications on behalf of caregivers
- Provide education and training for the provider community on working with caregivers who are using respite vouchers.
- Offer additional respite vouchers, using Project C.A.R.E. evaluation results to guide program improvement efforts.

