NC Division of Aging and Adult Services

Finding True North: The Transition of Project C.A.R.E

Dawn Oakey Gartman
Alzheimer’s Support Specialist / Project C.A.R.E Director

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Project C.A.R.E.  
*Caregivers Alternatives to Running on Empty*

**Objectives:**

- Path of discovery
- Describe the components of the Project CARE and the care consultation model
- Discuss successes and challenges of providing services to a growing population of older adults and their caregivers
Just a little history

• In 2001, Project C.A.R.E. began as a federally-funded demonstration grant, implemented in 6 counties, to develop systems and design services that support individuals with Alzheimer’s disease and their caregivers.

• Historically funded primarily from federal grants which ended in August 2013 (serving 40 counties at that time) and with $300,000 in state appropriations beginning in 2010.

• Since its inception the program has focused efforts on unpaid family caregivers who may be underserved:
  - Low income individuals/families  
    (those just above the Medicaid-eligible income level)
  - Minority members
  - Rural residents
National Recognitions

- 2008 - U.S. Administration on Aging (AOA) National Program Champion
- 2005 - AOA-Alzheimer’s Disease Supportive Services Program and RTI international - National Best Practice Model for “Implementing Systems and Sustained Change in Long Term Care”
- 2005 - National Alzheimer’s Association and National Model for Home and Community-Based Care Coordination - “National Innovative Program Clearinghouse Award”
- 2004 - Southeast Regional Geriatric Best Practices Award - “Developing Caregiver Support and Respite Programs”
Key program features

- Dementia-specific: responsive to the unique needs of dementia caregivers, provides expertise and understanding
- Consumer-directed services: annual spending cap; flexibility of frequency and duration; full continuum of respite care options
- Comprehensive support: referrals to other local services and supports
- Community network building: dementia-capable, mutually beneficial, increased quality of care
- Cost-effective: strengthens family care capacity, preserves caregiver health, prevents or delays early institutionalization, utilizes existing providers, boosts local economy
Post federal grants: 2013-2016

- Limited state funding; no respite
- 3 FTEs located in the Triangle, Asheville, and Greenville area
- Lack of standardization across sites
- Continued advocacy support by Senior Tarheel Legislators for increased recurring funding
- Task force on Alzheimer’s disease and related dementia convened in March 2015
- Dementia Capable North Carolina: A Strategic Plan
  - Raising awareness
  - Supportive options
  - Caregivers
  - Community life
  - Reaching the underserved
Project C.A.R.E. Expansion

• Recommendation 5.2 in the Dementia-Capable North Carolina: A Strategic Plan for Addressing Alzheimer’s Disease and Related Dementias
  
  *Ensure adequate funding for family caregivers support services, including dementia-specific respite through Project C.A.R.E.*

• New appropriation: Session Law 2016-94 effective October 1, 2016; $550,000 which annualized to $733,333 in SFY 2017-18.
  
  – Doubled family consultants from 3 FTE to 6 FTE equivalents
  – Provided respite funding
Case Management Pilot

Collaboration of Money Follows the Person (MFP) and Lifespan Respite Project to study effectiveness of multi-component caregiver supports and caregiver satisfaction.

- Care consultation model
- Adoption of new tools
  - Caregiver assessment
  - Action/care plan
  - Care planning tools
- Respite vouchers
  - $500
  - Up to 3 per SFY
  - 90-day period
  - Consumer-directed
State Objectives - Updated

• Implement consistent, standardized approach

• Introduce community-based supportive services to dementia caregivers

• Serve families in all 100 counties

• Effectively utilize the state funding to maximize support services

• Target those who may be underserved
  – Financially needy
  – Rural
  – Minority population
Core Components of Project C.A.R.E.

- Dementia-specific focus
- Family consultant role
- Consumer-directed services
- Flexibility
- Community network building
- Comprehensive support
- Public/private partnerships
Dementia-trained family consultants (6 FTE) and the Area Agencies on Aging (AAA) they collaborate within North Carolina
## Six Year Review SFY 2014-2019

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<tbody>
<tr>
<td><strong>Total Appropriation</strong></td>
<td>$300,000</td>
<td>$300,000</td>
<td>$300,000</td>
<td>$850,000</td>
<td>$1,033,333</td>
<td>$1,033,333</td>
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<td><strong>Care Consultation</strong></td>
<td>107</td>
<td>203</td>
<td>220</td>
<td>774</td>
<td>818</td>
<td>794</td>
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<tr>
<td><strong>Respite Care</strong></td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
<td>569</td>
<td>630</td>
<td>621</td>
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*Note: n/a indicates data not available.*
Who are family caregivers?

• Typical 49 year old married daughter with her own family and work outside of the home

• 83% of the help provided to older adults come from family members

• Nearly half of all caregivers (48%) provide help to older adults who live with Alzheimer’s or related dementia

• 473,000 caregivers in North Carolina provide care valued at $6.8 billion per year

• About 1 in 3 caregivers is age 65 or older

• Most caregivers live with the care recipient in community

Quick Stats!

• The number of North Carolinians with Alzheimer’s is expected to increase by 23.5% over 7 years – Alzheimer’s Association
  
  2018 – 170,000
  2025 – 210,000

• Many cases are underdiagnosed or underreported.

• 1 in 10 people over 65 and older has Alzheimer’s dementia

<table>
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<tr>
<th>Age</th>
<th>Prevalence</th>
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<tr>
<td>85 + years</td>
<td>38%</td>
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<tr>
<td>75-84 years</td>
<td>44%</td>
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<tr>
<td>65-74 years</td>
<td>16%</td>
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<tr>
<td>&lt; 65 years</td>
<td>4%</td>
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Project CARE FY2018 Impact

• 6 FTE Family consultants – experienced skilled, dementia-trained social workers regionally located
• Caregivers were served in 99 out of the 100 counties
• 818 caregivers have received care consultation services
• 630 of the 818 caregivers were awarded at least 1 respite voucher
• 67% of the caregivers (422 of 630) receiving respite were new to Project CARE
• 72% of these caregivers have received just one $500 voucher
• 73 vouchers were not used or have expired for various reasons (placement, hospitalization, death, couldn’t find a provider, or enrolled into other supports like CAP-DA, VA, HCCBG, etc.)
Caregiver Obstacles to Finding help

- Denial
- Guilt
- Feared loss of independence
- Feared loss of dignity
- Financial cost
- Lack of emotional support
- Lack of resources
- Caregiver stress
- Depression
- Familial role: “it’s my responsibility as a …”
Family Caregiving

• Care and supervision beyond that of a spouse, partner, daughter, son, friend, etc.
• Assist with instrumental activities of daily living
• Assist with activities of daily living
• Perform medical or nursing tasks
  • Medications
  • Help with assistive devices for mobility
  • Food preparation – special diets
  • Wound care
  • Use of meters/monitors
  • Use of incontinence supplies, equipment
  • Operate medical equipment
What we have learned

• Effective strategies to serve those with limited means and unmet needs
• Approaches with intensive contacts is overwhelming
• Simple, person-centered approach aimed at immediate needs of caregiver
• Action plan consists of achievable, realistic, and timely steps
• Coaching builds confidence
• Respite vouchers are not for everyone
• Follow up communication is key
• Collaboration with aging network and health providers
• Advocacy
Caregiver Feedback

• *I am not only the caregiver for my husband. I am also the caregiver for my mother who is 89 years old and father who is 90 years old. There is no one else but me to do this; that’s why I am so thankful for the program.*

• *If it had not been for respite care and support I would have had a breakdown and/or not had my husband at home as long as he was—so needed for all caregivers.*

• *The Family Consultant was extremely helpful. She explained the program and had to repeat things several times but never became inpatient with me. When the program started, I was very stressed but she encouraged me and kept giving me ideas on how to utilize the program to our benefit. I probably would not have followed through if it had not been for her. I am very pleased with the experience.*
Caregiver Feedback

- It is very expensive to hire home care, even a student is $15/hour. For someone on a tight budget, this is a lot of money. My husband is a full-time job without me having to go to work, so any amount of money that allows me to take a breather and hire someone is awesome. I have had minimum family support since he got sick. Also loss of all of his friends. That has been devastating. This [Project C.A.R.E.] has been a renewal of faith. Thank you!

- Because without the help your support gave me after surgery, I would have had to put my husband in a nursing home.

- I appreciated the opportunity to take some time for myself so that I could clear my mind, refresh and then take up my responsibilities again with a more positive attitude.

- The voucher that I received from the project helped me immensely. At the time it was awarded I was completely exhausted. I was so tired and it really helped me beyond measure.
Caregiver Feedback

- It was very beneficial because it is very costly paying out of pocket for respite services. The voucher allowed me to have some financial assistance as well as provided adequate care for my father with people that I trust.

- Sessions with our consultant were informative and gave us many options; she did not judge us as to our wishes or questions regarding care.

- Gives me a much-needed break to care for myself. Respite care consultants are the only ones that have ever helped with anything and I felt like somebody actually listened to me and cared. I have contacted other agencies I thought would be helpful. Not one time has anyone helped or even pretended to care or offered any kind of support or glimmer of hope for a better life as a caregiver. Thank you!
TRUE NORTH

• Life is about relationships
• Collaboration is necessary
• Simple, replicable approach
• Skilled, knowledgeable, professional family consultants
• Continual outreach
• Gratitude