

**JOINT LEGISLATIVE OVERSIGHT COMMITTEE
ON HEALTH AND HUMAN SERVICES -
SUBCOMMITTEE ON AGING**

Project C.A.R.E

Caregiver Alternatives to Running on Empty

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Project C.A.R.E

- 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 for Project C.A.R.E.

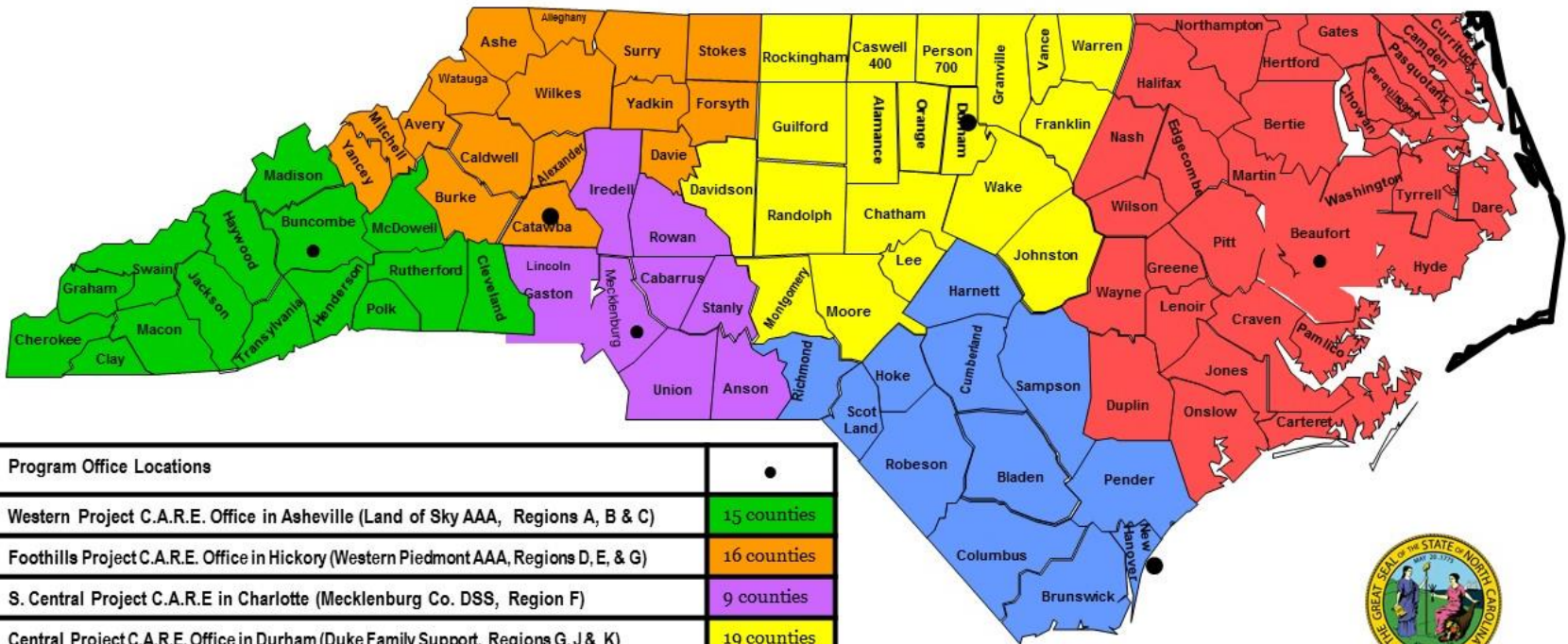
- 2008 - U.S. Administration on Aging (AOA) National Program Champion
- 2005 - AOA-Alzheimer's Disease Supportive Services Program and RTI international - National Best Practice Model for "Implementing Systems and Sustained Change in Long Term Care"
- 2005 - National Alzheimer's Association and National 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"

Project C.A.R.E

- Only state funded program supporting unpaid caregivers of persons living with Alzheimer's dementia or other related dementia(s)
- Utilizes a care consultation model providing information and referral services, dementia-specific education, caregiver assessment and care planning
- A respite voucher of \$500 (up to 3 vouchers per SFY) is awarded to case management caregivers who both need respite and lack financial resources

Project C.A.R.E

Dementia-trained family consultants (6 FTE) and the Area Agencies on Aging (AAA) they collaborate within North Carolina



Program Office Locations	●
Western Project C.A.R.E. Office in Asheville (Land of Sky AAA, Regions A, B & C)	15 counties
Foothills Project C.A.R.E. Office in Hickory (Western Piedmont AAA, Regions D, E, & G)	16 counties
S. Central Project C.A.R.E in Charlotte (Mecklenburg Co. DSS, Region F)	9 counties
Central Project C.A.R.E. Office in Durham (Duke Family Support, Regions G, J & K)	19 counties
S. Eastern Project C.A.R.E. Office in Wilmington (Cape Fear AAA, Regions M, N, & O)	12 counties
N. Eastern Project C.A.R.E. Office in Washington (Mid-East AAA, Regions L, P, Q, R)	29 counties



NC Division of Aging and Adult Services
July, 2017

Core Components

- **Dementia-specific focus**
- **Family consultant role**
- **Consumer-directed services**
- **Flexibility**
- **Community network building**
- **Comprehensive support**
- **Public /private partnerships**

SFY 2016-17 Highlights

Session Law 2016-94 included a new appropriation of \$550,000 effective October 1, 2016:

1) Doubled family consultants from 3 FTE to 6 FTE equivalents

2) New respite funds:

- \$271,942 of the \$550,000 plus an additional \$44,501 from Money Follows the Person provided respite vouchers for caregivers
- 774 unpaid family caregivers received care management
- 569 of the 774 caregivers were awarded at least one \$500 respite voucher
- Caregiver services provided in underserved counties
- Served at least 1 caregiver in 94 counties (unserved counties: Graham, Davie, Lee, Person, Tyrrell, Yadkin)
- Expanded caregiver-directed respite options include hiring an individual, home care agency, adult day care, group respite, or institutional facility

Five Year Review SFY 2013-18

Number of Family Caregivers Served					
State Fiscal Year	2013-2014	2014-2015	2015-2016	2016-2017	2017-2018 <i>(Estimates)</i>
NC Appropriation	\$300,000	\$300,000	\$300,000	\$850,000	\$1,033,33
Care Management	107	203	220	774	800
Respite Care (care management clients who also received respite)	n/a	n/a	n/a	569	650

New appropriation: Session Law 2016-94 effective October 1, 2016; \$550,000 which annualized to \$733,333 in SFY 2017-18.

Current Progress SFY 2017-2018

For the first 7 months:

- 498 unpaid family caregivers in 94 counties receiving case management and respite vouchers
- 305 of the 498 caregivers (61%) new since July 1, 2017
- 83% caregivers received only one \$500 respite voucher
- 75% of the vouchers have been awarded
- Wait list of 126 caregivers for new enrollment
- At least 40 caregivers are waiting for additional respite
- Anticipate all respite funds awarded by April 1, 2018

Recent Successes

- **New strategies employed:**
 - Introduced structured case management model (coaching)
 - Comprehensive service provides better outcomes (improves caregiver well-being; reducing burden, stress, depression, and poor health issues)
 - New collaboration opportunity with frequent and consistent communication
 - System transparency
- **Expansion to 100 counties (94 out of 100 counties previously served)**
- **Introduced caregivers to care management and respite along with community resources and services**

Challenges

- **Staff capacity (6 FTEs) - difficult to meet service needs in large, multi-county territories**
- **Limited respite funds (awarded in the most financially needy cases)**
- **76 vouchers went unused in SFY 2017 due to various issues**
- **Wait list due to both staff capacity and funding**
- **Single \$500 voucher does not purchase much service**
- **Finding respite providers in rural counties**

Average Annual Payments for Health & Long-Term Care

Payment Source	Beneficiaries with Alzheimer's or Other Dementias	Beneficiaries without Alzheimer's or Other Dementias
Medicare	\$ 23,497	\$ 7,223
Medicaid	8,182	349
Uncompensated	364	365
Health maintenance organization	1,205	1,475
Private insurance	2,152	1,358
Other payor	895	231
Out of pocket	10,315	2,232
Total	\$46,786	\$ 13,351

SOURCE: : Alzheimer's Association 2017 Alzheimer's Disease Facts and Figures - Average Annual per-Person Payments for Health Care and Long-Term Care Services, Medicare Beneficiaries Age 65 and Older, with and without Alzheimer's or Other Dementias, in 2016 Dollars

Advocates' Recommendations

The Senior Tar Heel Legislature, with support from the NC Alzheimer's Association, advocates for an increase in recurring funding for Project C.A.R.E. by ten percent annually to meet the expected statewide growth.

Supporting Facts:

- The number of North Carolinians with Alzheimer's is expected to increase by **31%** over 8 years from **160,000 (2017)** to **210,000 (2025)**
- A care recipient living with Alzheimer's dementia typically lives an average of **4-8 years** after diagnosis but may live for up to **20 years**; **40%** of time in most severe stage
- Of those in nursing homes, **2/3** die with dementia as compared to **20%** with cancer or **28%** dying with other issues
- **\$1.112 Billion** in dementia-related Medicaid costs expected for **2017** in North Carolina