

## STATE OF NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES

ROY COOPER GOVERNOR MANDY COHEN, MD, MPH
SECRETARY

October 1, 2019

## SENT VIA ELECTRONIC MAIL

Mark Trogdon Fiscal Research Division North Carolina General Assembly 619 Legislative Office Building Raleigh, NC 27603-5925

Dear Director Trogdon:

Session Law 2010-31, Section 10.35B requires the Division of Aging and Adult Services (DAAS), as part of the Department of Health and Human Services, to develop and implement a plan for use of recurring funds to support Alzheimer's related activities consistent with the goals of Project C.A.R.E (Caregiver Alternatives to Running on Empty). This report is to be submitted annually to the Governor's Advisory Council on Aging and the Fiscal Research Division by no later than October 1 of each year. Originally, this Senate Bill also called for the report to be submitted to the NC Study Commission on Aging, which is no longer in existence.

The Division regularly reports on the status of Project C.A.R.E to the Governor's Advisory Council on Aging. Attached is a summary report of Project C.A.R.E as a statewide approach to support the needs of caregivers of those with Alzheimer's and related dementias.

Should you have any questions regarding this report, please contact Joyce Massey-Smith, Director for the Division of Aging and Adult Services, at 919-855-3400.

Sincerely,

Mandy Cohen, MD, MPH

Tara Myers

Secretary

cc:

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# Project C.A.R.E. (Caregiver Alternatives to Running on Empty)

## Session Law 2010-31, Section 10.35B



## Report to

# The Governor's Advisory Council on Aging and The Fiscal Research Division

by

North Carolina Department of Health and Human Services Division of Aging and Adult Services

**October 1, 2019** 

#### Project C.A.R.E 2018-2019

Over 5 million Americans are living with Alzheimer's Disease nationally and as many as 14 million will have the disease by 2050. The Alzheimer's Association projects that by 2025, an estimated 210,000 North Carolinians (age 65 and older) will have Alzheimer's disease, a 23.5% increase from 170,000 persons in 2019. It is also estimated that 473,000 caregivers in North Carolina provided unpaid care valued at approximately \$6.8 billion in 2018. The costs of health care and long-term care services for individuals living with dementia is substantially higher then someone without dementia which places a financial burden along with the physical, emotional, and social challenges families encounter with dementia caregiving.

Pursuant to Section 10.35B of Session Law 2010-31 (Senate Bill 897), the North Carolina Department of Health and Human Services (DHHS), Division of Aging and Adult Services (DAAS) implemented a plan for use of \$200,000 in recurring state appropriations to support Alzheimer's-related activities consistent with the goals of Project C.A.R.E. (Caregiver Alternatives to Running on Empty). The session law called for an annual report to be submitted to the Governor's Advisory Council on Aging and the Fiscal Research Division by October 1st each year. Originally, this Senate Bill called for the report to also be provided to the North Carolina Study Commission on Aging, which is no longer in existence.

#### Statewide Caregiver Support

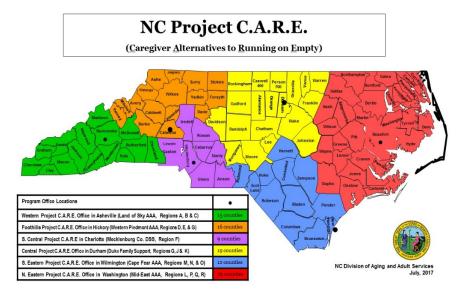
Project C.A.R.E. is a state-funded, dementia-specific support program for individuals who directly care for persons with Alzheimer's disease or related dementias. Project C.A.R.E. utilizes a coordinated delivery system that is responsive to the needs, values and preferences of unpaid family caregivers and is administered by the DHHS Division of Aging and Adult Services.

The expansion of Project C.A.R.E. in the fall of 2013 and again in October 2016, facilitated the growth of the program from 36 counties to all 100 counties. DAAS continues to recognize the importance of reaching individuals living with dementia and their unpaid caregivers as an essential step to meeting the long-term program objective of providing support for the significant increase in the number of caregivers of those individuals living with dementia. The key goal of Project C.A.R.E. is to provide supports for unpaid caregivers of individuals with Alzheimer's disease and related dementias to support community living and to delay or avoid unnecessary placement in long-term care facilities.

Project C.A.R.E. contracts with six community-based organizations to provide family consultant services to all 100 counties. Family consultants collaborate closely with the sixteen Area Agencies on Aging (AAA) and the Family Caregiver Support Programs. This allows for available resources to be coordinated and leveraged for maximum impact. Family consultants provide support directly to caregivers of persons living with Alzheimer's disease and other related dementias by:

- 1. Offering caregivers of persons living with dementia care consultation services: dementia-specific information, caregiver assessments and individualized care plans, caregiver education and connections to social support networks;
- 2. Linking families with available community resources to address unmet needs including local support groups, supportive services, entitlement programs and other community resources;
- 3. Partnering with each Area Agency on Aging through its Family Caregiver Support Program to provide outreach, training and education;
- 4. Providing caregivers consumer-directed respite care vouchers (\$500 each) whereby the caregiver decides who, when and where to hire help;
- 5. Providing training and assistance to AAAs and the community-at-large to increase capacity to assist persons with dementia and their families; and

6. Enhancing partnerships with and among the various entities serving persons living with Alzheimer's disease and assisting their caregivers.



## Service Delivery

The NC General Assembly, in 2014, required the NC Department of Health and Human Services, Division of Aging and Adult Services to develop the state's first strategic plan addressing Alzheimer's disease and related dementias (Senate Bill 744 / S.L. 2014-100). In response, the Division, in partnership with the NC Institute of Medicine, along with a 47-member task force, completed a plan in March 2016 titled "Dementia Capable North Carolina" which included the recommendation for increased support of Project C.A.R.E. The Governor and the General Assembly approved the appropriation of additional funds through Session Law 2016-94 (House Bill 1030). Effective October 1, 2016, \$550,000 was appropriated to support three additional Project C.A.R.E. Family Consultants and to provide funding for respite care vouchers for unpaid family caregivers and this amount was annualized to \$733,333 currently.

In State Fiscal Year 2019, Project C.A.R.E. provided care consultation services to 831 non-Medicaid family caregivers of which 550 caregivers received respite care vouchers; 475 or 74% of those receiving respite were new to the program this year. A caregiver may receive up to three \$500 vouchers annually however 60% of the 550 caregivers were awarded a single voucher as compared to 72% in FY 2018. Consumer-directed respite services were performed based upon the needs and wishes of the unpaid caregiver with service options including in-home respite services, group respite (adult day care/adult day health care), or in special cases, overnight facility-based care. Project C.A.R.E. reached caregivers in 99 counties in FY 2019. As of June 30, 2019, approximately 147 unpaid family caregivers were waiting to enroll into Project C.A.R.E. and many enrolled caregivers were requesting additional respite. The six FTE Project C.A.R.E. family consultants work at their fullest capacity effectively utilizing 99% of the state appropriation.

Number of Family Caregivers Served					
	2014-2015	2015-2016	2016-2017	2017-2018	2018-2019
Total Appropriation	\$300,000	\$300,000	\$850,000	\$1,033,333	\$1,033,333
Care Consultation	203	220	774	818	831
Respite Care (care consultation clients who also received State funded respite)	n/a	n/a	569	630	550