

**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

May 18, 2023

Project C.A.R.E 2021-2022

Background

The Alzheimer's Association projects that by 2025, an estimated 210,000 North Carolinians (age 65 and older) will have Alzheimer's disease, a 16.7% increase from 180,000 persons in 2020. Medicaid costs are projected to increase 22.2% during this five-year period for persons with Alzheimer's disease. In North Carolina, much of the daily care provided is by an estimated 369,000 unpaid caregivers with the cost of care valued at approximately \$8.1 billion in 2022. In 2019, 4,508 deaths were reported due to Alzheimer's disease which is a 161.3% increase in Alzheimer's deaths since 2000. The costs of health care and long-term care services for individuals living with dementia is substantially higher than for those without dementia, which adds a financial burden to 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 the 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 required 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 (ARD). Started in 2016, Project C.A.R.E. is administered by DAAS and serves all 100 counties. The program supports family caregivers of people living with Alzheimer's disease or other related dementia(s). Project C.A.R.E. utilizes a care consultation model providing information and referral services, dementia specific education, caregiver assessment, and care planning.

A key goal of Project C.A.R.E. is to provide services for dementia caregivers enabling their care recipients to age in place and to delay or avoid unnecessary placement in long-term care facilities. DAAS continues to recognize the importance of unpaid caregivers as an essential partner to address the quality of life needs and well-being for all older adults, and particularly those of individuals with greater challenges and higher level of needs. The COVID-19 pandemic elevated the need for supports for unpaid family caregivers and direct care workforce shortages.

Project C.A.R.E. contracts with six community-based organizations to provide care consultation services in all 100 counties, as shown in Figure 1. Family consultants collaborate closely with the sixteen Area Agencies on Aging (AAA) and the Family Caregiver Support Program. This relationship allows for available, local resources to be coordinated and leveraged for maximum impact. Family consultants provide support directly to caregivers of persons living with ARD 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 AAA 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 AAA 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.



Figure 1. NC Project C.A.R.E. Regional Office locations

Service Delivery

The NC General Assembly, in 2014, required DAAS 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 for the state fiscal year ending June 30, 2016. Effective July 1, 2016, the amount was annualized to \$733,333.

In State Fiscal Year 2022, Project C.A.R.E. provided care consultation services to 569 non-Medicaid family caregivers in 90 counties, as shown in Table 1. The six FTE Project C.A.R.E. family consultants work at full capacity effectively utilizing 97.5% of the state appropriation. All of

the respite budget was utilized for direct services. As of June 30, 2022, approximately 75 unpaid family caregivers (a waitlist reduction from 133 in FY2021) were waiting to enroll into Project C.A.R.E. and many enrolled caregivers were requesting additional respite support.

Of the 569 non-Medicaid family caregivers served, 495 caregivers received respite care vouchers; 331 (67%) of those receiving respite were new to the program this year. A caregiver may receive up to three \$500 vouchers annually. In FY 2022, 46% of the 495 caregivers were awarded 2 or 3 vouchers compared to 48% in FY 2021, and 36% in FY 2020. 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. was fortunate to receive additional, one-time only federal funds to provide much needed respite in the second half of the state fiscal year. Through June 30, 2022, 176 caregivers had benefited from care consultation and respite services as a result of the federal funds. The grant was active when this report was written, however, it is anticipated that up to \$148,000 will be expended for direct respite services by August 30, 2022.

Number of Family Caregivers Served* ¹							
	2021-2022	2020-2021	2019-2020	2018-2019	2017-2018	2016-2017	2015-2016
Total State Appropriation	\$1,033,333	\$1,033,333	\$1,033,333	\$1,033,333	\$1,033,333	\$850,000	\$300,000
State Funded Care Consultation	569	572	722	831	818	774	220
Respite Care (Care consultation clients who also received State funded respite)	495	484	586	550	630	569	n/a

Table 1. Family Caregivers Served through Project C.A.R.E. state appropriations.

¹ The decrease in the number of respite vouchers provided in FY 20-21 and FY 21-22 can be attributed to challenges associated with service delivery during the COVID-19 pandemic as a result of the direct care workforce shortage.