

**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**

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Project C.A.R.E 2023-2024

Background

The Alzheimer's Association estimates 210,500 North Carolinians (age 65 and older) have Alzheimer's disease. 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 373,000 unpaid caregivers with the cost of care valued at approximately \$10.9 billion in 2023. In 2021, 4,260 deaths were reported due to Alzheimer's disease which is a 147% 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 (DA) implemented a plan to use \$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 no longer exists.

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. Started statewide in 2016, Project C.A.R.E. is administered by DA and is available in all 100 counties. Project C.A.R.E. utilizes a family consultant model of care consultant and provides information and referral services, dementia specific education, caregiver assessment, caregiver respite vouchers, 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. The DA 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.

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.

Project C.A.R.E. family consultants provide support directly to caregivers of persons living with Alzheimer's disease and related dementias by:

1. Offering care consultation services that include 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 caregiver-directed respite care vouchers (\$500 each) to caregivers 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.



Figure 1. NC Project C.A.R.E. Regional Office locations (SFY2023-2024)

Service Delivery

In 2014 the NC General Assembly required the DA to develop the state’s first strategic plan addressing Alzheimer’s disease and related dementias (Senate Bill 744 / S.L. 2014-100). In partnership with the NC Institute of Medicine and a 47-member task force, the DA completed a plan in March 2016 titled “Dementia Capable North Carolina,” which included a 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 total recurring appropriation was annualized \$1,033,333.

In State Fiscal Year 2024, Project C.A.R.E. provided care consultation services to 502 non-Medicaid family caregivers in 86 counties, as shown in Table 1. The six FTE Project C.A.R.E. family consultants work at full capacity effectively utilizing 100% of the state appropriation. All the respite budget was utilized for direct services.

Of the 502 non-Medicaid eligible family caregivers served, 428 caregivers received respite care vouchers; 272 (64%) of those receiving respite were new to the program this year. A caregiver may receive up to three \$500 vouchers annually. In FY 2024, 40% of the 428 caregivers were awarded and utilized 2 or 3 vouchers. Consumer-directed respite services were delivered based upon the needs and wishes of the unpaid caregiver with service options including an individual respite worker, home care agency, group

respite (adult day care/adult day health care), or in special cases, overnight facility-based care. In FY2024, 85% of caregivers chose to hire an individual to provide in-home respite services.

The decrease in number of caregivers served through Project C.A.R.E. with respite and care consultation services can be attributed to compounding issues including increased difficulty to find care providers due to the direct care workforce shortage, increasing costs for host agencies with flat or constant funding, and increased complexity of care consultations and more complex caregiver needs requiring additional hours of time by the program Family Consultants. The demand for services continues to be greater than the supply through Project C.A.R.E.

Project C.A.R.E. Appropriation and Service Delivery by Fiscal Year (2018-2024)

| State Fiscal Year | 2024 | 2023 | 2022 | 2021 | 2020 | 2019 | 2018 |
|---------------------------------------|------|------|------|------|------|------|------|
| State-Funded Care Consultation | 502 | 593 | 569 | 572 | 722 | 831 | 818 |
| Respite Care* | 428 | 463 | 495 | 484 | 586 | 550 | 630 |

**All caregivers that receive respite services also receive care consultation*

Data source: NC DHHS Division of Aging