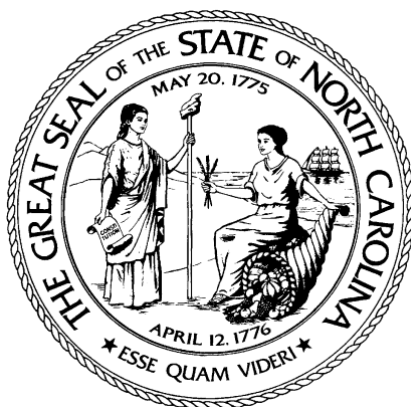


**Project C.A.R.E.
(Caregiver Alternatives to Running on Empty)**

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, 2021

Project C.A.R.E 2020-2021

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 care provided is by an estimated 358,000 unpaid caregivers with the cost of care valued at approximately \$7.3 billion in 2020. The Alzheimer's Association also estimates an increase of 1,082 more deaths in 2020 or 11.3% higher than average during the COVID-19 pandemic. 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 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 (ADRD). 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 (DAAS).

State funding for Project C.A.R.E. in the fall of 2013 and again in October 2016, facilitated the expansion of the program from 36 counties to all 100 counties. 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. Given the current pandemic environment, this program highlights the importance of unpaid and familial supports. 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.

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



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 2021, Project C.A.R.E. provided care consultation services to 572 non-Medicaid family caregivers of which 484 caregivers received respite care vouchers; 318 or 66% of those receiving respite were new to the program this year. A caregiver may receive up to three \$500 vouchers annually however 48% of the 484 caregivers were awarded 2-3 vouchers compared to 36% in FY 2020 and 40% in FY 2019. 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 97 counties in FY 2021. As of June 30, 2021, approximately 133 unpaid family caregivers (up from 115 in FY2020) 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 94% of the state appropriation; 99% of the respite budget was utilized for direct services.

It is hard not to mention the impact that the COVID-19 pandemic has made on the Project C.A.R.E. program, it's staff and the caregivers served throughout the state. The Family Consultants transitioned to strictly utilize telephonic communications verses the initial home visits typically conducted. They noticed

it was harder to complete assessments, for caregivers to hire a respite provider and that caregivers had more difficulties completing the required paperwork for reimbursement of services. They also encountered an increase of stress, burden and social isolation amongst caregivers due to the pandemic restrictions. Some caregivers were offered new digital and video opportunities for support groups and training however internet access and lack of technological skills detracted some for the use of these tools.

Programmatically, travel expenses decreased, and a portion of the funds was repurposed for respite. Some caregivers needed more respite as noted by the increase in caregivers receiving 2-3 voucher awards. A few caregivers needed more respite than the \$1500 cap the program provided and thus were referred to other programs. As an outcome of the caregivers' increased physical, emotional and social strain, the Family Consultants also endured increased stress from the communications with these individuals and as options of support dwindled. Community-based services such as face-to-face support groups, adult day care and in-home assistance were less available. Work styles and environments were changing throughout the pandemic and safety precautions needed to be employed by all individually and organizationally.

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