

LGFCU Excellence in Innovation Award Project Evaluation

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County	Mecklenburg
Employee	Renee Dutcher
Employee title	Program Manager
Email	Renee.dutcher@mecklenburgcountync.gov
County Department	Mecklenburg County Department of Social Services
Phone	980-314-6121
Address	301 Billingsley Road Charlotte, NC 28211
County Manager	Dena Diorio
Supervisor	Darrell Cunningham
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FLSA Designation	Exempt
Project Team Members	Darrell Cunningham, Division Director Renee Dutcher, Program Manager Patricia Mayhew, Program Coordinator Ashley Stevens, Project C.A.R.E. Social Worker

Description of Productivity Improvement

The number of North Carolinians afflicted with Alzheimer's disease, now approximately 170,000, will double in the next 10 years. Alzheimer's disease is the 5th leading cause of death in the state. The NC Division of Aging and Adult Services continues to develop and enhance models of care that encourage and support families as they assist their aging family members and loved-ones to remain at home for as long as possible. Project C.A.R.E. was designed and tested in North Carolina. It has become a national best practice model for providing support to family members who are caring at home for a loved-one with Alzheimer's disease or related dementia. Project C.A.R.E is the only state funded dementia-specific service that uses a family consultant model to provide comprehensive support to dementia caregivers. The goal of the program is to increase quality, access, choice, and the use of respite care for low-income (non-Medicaid), rural and minority families caring for a person with dementia at home.

The Mecklenburg County Department of Social Services was selected by the North Carolina Division of Aging and Adult Service-Division of Health and Human Services to be the lead agency in a 9-county region (Centralina includes Mecklenburg, Anson, Union, Stanley, Cabarrus, Rowan, Iredell, Lincoln, and Gaston). The Project began educating the community partners, conducting both home visits and

phone contacts with caregivers and assisting with the submission of Respite Vouchers in October 2016.

From October 2016 to April 2017 the Project C.A.R.E. consultants in Mecklenburg County contacted 1,167 family caregivers and professionals to inform them about the program. These contacts not only helped inform individuals about the Project C.A.R.E. program but also helped to raise awareness about caregiving and dementia. This program is strong because it does not work in isolation but partners with other agencies to form a broader support network for caregivers.

Family caregivers of those with dementia from our 9-county region were given a total of 97 respite vouchers worth up to \$500 each. These vouchers were used by caregivers for respite and care for their loved ones.

Project C.A.R.E. family consultants work together with other agencies and the state to provide high quality information and care management to those caregivers taking care of loved ones with dementia. Project C.A.R.E. consultants partnered with other agencies to leverage and pool resources. For example, Trinity Living Center in Rowan County provides an Adult Daycare for caregivers to take a break from their caregiving duties. The Project C.A.R.E. family consultant and supervisor partnered to have a caregiving event at Trinity Living Center where Project C.A.R.E. assessments could be done with caregivers and respite vouchers provided. This decreased travel time. Project C.A.R.E. staff at Mecklenburg County DSS collaborate with the staff in the Community Resource and Services for Adults Divisions to refer families who qualify for the program. This increases productivity and allows for greater attention and time to be spent with caregivers affected by Alzheimer's disease with a qualified dementia Family Consultant.

Description of why this project was initiated

Alzheimer's disease is something that affects so many of us. We North Carolinians are sensitive to this as it affects one in seven of us over the age of 65. Here in our home state, there are over 160,000 people living with Alzheimer's disease and it is the 5th leading cause of death. Since it is also the only top 10 cause of death that cannot be cured, prevented or slowed, we recognize the importance to address the needs of the individuals and their loved ones who are impacted now.

In 2014, the NC General Assembly issued a Mandate to NC Stakeholders to develop a strategic plan in response to the increasing needs of the families affected by Alzheimer's and other dementias. In response to the Mandate, the North Carolina Institute of Medicine partnered with the North Carolina Department of Health and Human Services Division of Aging and Adult service, AARP NC, Alzheimer's NC, the Alzheimer's Association, the Duke Endowment, the Winston-Salem Foundation and LeadingAge NC creating a Task Force. In 2015, this Task Force convened to develop an actionable strategic plan with the following goals in mind: to improve statewide awareness and education about Alzheimer's disease and related dementias; support people with dementia and their families; improve and enhance services that support greater quality of life; reach underserved population; and improve data collection and research around treatment and prevention of Alzheimer's disease and related dementias.

Out of this partnership, the NC Division of Aging and Adult Services and Task Force developed Dementia-Capable North Carolina: A Strategic Plan addressing Alzheimer's disease and related dementias in March 2016. In response to the recommendations contained in this report, the NC General Assembly appropriated \$550,000 additional recurring state funds to expand the existing NC Project C.A.R.E. (Caregiver Alternatives to Running on Empty). Specifically, the funds added three (3) full-time Family Consultant positions throughout the state and provided funding for respite care for caregivers of persons with Alzheimer's disease and related dementias.

Mecklenburg County Department of Social Services applied for and was awarded one of the additional Family Consultant positions. Beginning in October 2016, Mecklenburg County DSS became the lead for the 9 county Centralina Project C.A.R.E region in North Carolina.

Project C.A.R.E. is a coordinated delivery system that is responsive to the needs, values and preferences of families who take care of family member's with Alzheimer's disease. Specifically a family consultant provides the following services:

- Offers persons with dementia and their caregivers counseling, care consultation, dementia-specific information, caregiver assessments, caregiver education and connections to strong social support networks
- Connects families with available community resources in an attempt to meet unmet needs of family caregivers including local support groups, supportive services, entitlement programs and other community resources
- Partners with each regional Family Caregiver Support Program Specialist for cross-referrals and co-outreach, training and education
- Provides training and assistance to the community-at-large to increase capacity to assist persons with dementia and their families
- Enhances partnerships with and among the various entities serving persons with Alzheimer's disease and assisting their caregivers
- Assists to implement the Dementia Capable State Plan spearheaded by the Division of Aging and Adult Services (DAAS) in collaboration with identified partners

Mecklenburg County DSS quickly operationalized the Project C.A.R.E program. We received our award letter on October 19, 2016. The family consultants and supervisors met with the state Project C.A.R.E. administrators on 10/24/17 in Raleigh to finalize the assessment tools and paperwork. The first caregiver was contacted on 10/25/17 and notified about the program.

The Family Caregiver Support Program, Home and Community Block Grant programs, Medicaid waiver programs and other service programs for caregivers and their loved ones have waiting lists. Some waiting lists are years long. This opens opportunity for a program such as Project C.A.R.E. to fill the gaps and serve many of these families placed on long waiting lists.

Caregiving for someone with dementia can be an isolating, stressful experience. Literature strongly supports the value of assessing the needs of family caregivers and addressing those needs in a plan of care. If family caregivers are not connected to needed services and supports, their own health and well-being may be compromised, increasing the risk that they will not be able to continue to provide care in the community.

Partnerships with other agencies can help stretch and leverage resources. For example, Mecklenburg County Project C.A.R. E. has a strong relationship with the local Alzheimer's Association. The Alzheimer's Association has a 24/7 helpline, on-line trainings for caregivers, support groups and a Medic Alert + Safe Return safety Program for individuals who wander. These types of partnerships allow cost savings as agencies pool and leverage resources. Family consultants are also able to

collaborate with the Association on education, care, and support efforts for caregivers, allowing caregivers to be better informed of the disease process and how to care for themselves. The Project C.A.R.E. assessment is thorough and the Family Consultants help caregivers look for additional resources that may help keep their loved one at home for the long term. Close partnerships with Hospice, Medicaid, Veterans Administration, CAP, PACE, Lifespan Respite grant, Family Caregiver Support and other programs allow for the most efficient planning and utilization of resources. Caregivers are empowered to build their own informal support systems that will provide respite and support. For example, one caregiver's church agreed to pay for one day a week of daycare for her loved one. Family consultants coach the caregivers on skills to utilize when asking for and receiving help. They are also coached on how to use and stretch any financial resources they may have that can be used for respite and care of their loved one. Many caregivers are very grateful for the program and have said that the care management and respite vouchers have allowed them to continue caring for their loved one in the home. It is very common for caregivers to report that their mental and physical health was in jeopardy before the program. They report that the program is truly a lifesaver.

Quantifiable results (sustainability, cost savings, cost avoidance and/or a higher level of service).

Indication of what resources were used and what was done with any accrued time savings

Mecklenburg County DSS hired a new full time employee with extensive experience with Alzheimer's disease to focus solely on this program. During the first 6 months of the program, we have spent approximately \$36,000 in salary, administrative and startup costs. In addition, we have awarded 97 Respite vouchers valued at nearly \$50,000. The respite vouchers provided represented a fraction of the cost of placing an individual with dementia in a facility. A Special Care Unit for someone with dementia costs between \$5,000-\$7,000 per month. Nursing Home costs often exceed \$8,000 per month. For example, by providing up to three \$500 vouchers at a maximum cost of \$1,500 per year, this program can save Medicaid tens of thousands of dollars each year by keeping someone out of a nursing home. Dementia is one of the most expensive diseases because the disease process averages eight to ten years after diagnosis. It takes an average of 2.8 years after symptoms begin to get diagnosed. The need for supervision is paramount with dementia and this need drives up the cost. In addition, challenging behaviors such as wandering and falls are costly. For example, 60% of those with dementia will wander away from home and if the person is not found within 24 hours, half will suffer serious injury or death. When a person wanders the police often have to use a search helicopter and use financial and staff resources trying to find the person. Fire and medic also get involved. The wandering person often falls necessitating an emergency room visit and perhaps costly hospitalization. Family consultants can help prevent these incidents by coaching the family on how to prevent, anticipate and handle these behaviors. The Project C.A.R.E. consultants assess for and help the caregiver with a wide range of challenging behaviors that are typical for those with dementia. Mecklenburg County's Family Consultant for our 9-county region has a tremendous impact on families affected by dementia. The incidence of Adult Protective Services and other costly social work and legal interventions can decrease because of the early preventative focus of the intervention on the caregiver. By design, Project C.A.R.E., as with all programs under the Older Americans Act, are expected to target as well as prioritize community-based services for those older adults at the greatest risk. These

priority groups include low-income, rural and/or minority older adults and caregivers. 61% of our caregivers were minority. Care recipients eligible for Medicaid are encouraged to utilize Medicaid covered programs. 16% of our caregivers are below poverty level. Before the program they often had to quit their jobs, cut their work hours or retire early to caregiver for their loved one.

Other descriptive information

This program has a tremendous positive impact on caregivers, and in turn, their loved ones are better cared for which increase the overall quality of the care provided. Family Consultants assist caregivers to understand and value the importance of self-care and caregiver satisfaction. This is attainable by engaging in care planning, in-depth discussions, and therapeutic interventions. Family Consultants work closely with families to understand the value of respite and how to truly maximize their respite vouchers, by setting realistic goals and expectations of themselves and their loved ones. This allows for caregivers to tap into pleasurable activities they often miss out on due to the heavy burden of caring for their loved one. Caregivers who maximize their respite time to do what they intended to do often feel less burden and more satisfaction with their caregiving role.