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Alzheimer's Disease Demonstration Grants to States Program: North Carolina

Final Report

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EXECUTIVE SUMMARY

The Alzheimer's Disease Demonstration Grant to North Carolina is a partnership among the Division of Aging and Adult Services in the North Carolina Department of Health and Human Services, the Duke University Center for the Study of Aging and Human Development Family Support Program, the Western Carolina Chapter of the Alzheimer's Association, the Mecklenburg County Department of Social Services, and the Area Agencies on Aging for Regions B, C, F and I.

The Grant funds Project C.A.R.E. (Caregiver Alternatives to Running on Empty), which created a community-based, family-centered service system that provides direct access to dementia-specific respite care and connects families to other long-term care services. Project C.A.R.E. targets an underserved rural, minority and low-income elderly population. It demonstrates that both public and private entities can deliver dementia-specific respite services, allowing communities to administer the program in a way that is best suited to local circumstances.

Project C.A.R.E. offers families a personalized approach to respite care. Through Family Consultants, families are offered in-home assessment and care planning, a simplified determination of eligibility, a wide degree of flexibility and choice in the use of respite funding, and ongoing case management. The Family Consultants also provide education and training for caregivers and respite providers and serve as a link for families to other long-term care resources. Family Consultants develop networks of provider, governmental, and volunteer agencies to bring quality dementia-specific respite services to caregivers.

To achieve systems change, Project C.A.R.E. has used a number of strategies:

- Integrating the needs of family caregivers into public programs and long-term care planning. Through cooperation in strategic planning and collaboration with other state programs serving caregivers at the state level and the work of the Family Consultant in building networks of providers at the local level, Project C.A.R.E. has helped create a state long-term care system that recognizes the caregiver's needs and preferences as well as those of the person with dementia.

- Exploring the efficacy of varying administrative sponsorship. Project C.A.R.E. demonstrated its effectiveness in two different administrative settings: under the guidance of an Alzheimer's Association Chapter and as part of a unified county social services agency.

- Increasing access and availability of a comprehensive range and type of dementia-specific respite services by using the Family Consultant model. Under Project C.A.R.E., the Family Consultant develops agency partnerships, recruits and trains service providers, publicizes the availability of caregiver services, conducts in-home assessments, facilitates the connection between the caregiver and respite care options and providers, and provides continuing support to caregivers and providers.

- Offering consumer choice and consumer-directed respite care. Project C.A.R.E. provides flexibility in meeting the caregiver's needs through individualized attention and multiple options in the type, scheduling, and staffing of respite services.

- Conducting outreach to rural, minority, and low-income families. Project C.A.R.E. targets underserved rural, minority and low-income elderly populations. By developing personal contacts and building bridges to the faith-based community, Family Consultants have helped overcome the cultural and geographic isolation facing dementia caregivers in rural mountainous areas and urban minority communities.

- Connecting families with information and services. Project C.A.R.E. is bringing the expertise of the Alzheimer's Association and other proven resources into the community arena, educating caregivers and providers about techniques that produce a higher quality of life for the client and caregiver. The network development work of the Project C.A.R.E. Family Consultants also puts them and the project in a unique position to link caregivers to a wide range of long-term care services and supports.

- Leveraging Alzheimer's Disease Demonstration Grants to States (ADDGS) funds for sustainability. The Grant partners are making a diligent effort to identify resources to sustain Project C.A.R.E. by seeking private foundation funding, collaborating with other long-term care grants, and making plans to approach state legislative staff with evidence of the project's effectiveness. In the Mecklenburg County site, Project C.A.R.E. demonstrated its value to a local agency that is willing to support the Family Consultant function and be an advocate for county-level respite funding.

Project C.A.R.E. is a replicable model for state and local governments to consider. Through this Alzheimer's Disease Demonstration Grant, Project C.A.R.E. has brought dementia-specific respite services and resources to family caregivers of persons with Alzheimer's disease and other dementias, with the flexibility to meet the needs of caregivers in different economic, cultural, and geographic settings.

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INTRODUCTION: OVERVIEW OF ADDGS PROGRAM AND CASE STUDIES

Alzheimer's disease is a devastating degenerative disease that causes memory loss, challenging behavior problems, and severe functional limitations. A person with late-stage Alzheimer's disease requires constant supervision, support, and hands-on care. While many persons with Alzheimer's disease are admitted to nursing homes, the majority of people with the disease live in the community, where their families provide most of the care.

To improve services to persons with Alzheimer's disease, Congress established the Alzheimer's Disease Demonstration Grants to States (ADDGS) program, which is administered by the U.S. Administration on Aging. The program's mission is to "expand the availability of diagnostic and support services for persons with Alzheimer's disease, their families, and their caregivers, as well as to improve the responsiveness of the home and community-based care system to persons with dementia. The program focuses on serving hard to reach and underserved people with Alzheimer's disease or related disorders (ADRDs)" (U.S. Administration on Aging, no date).

This paper discusses one of five case studies conducted by the ADDGS National Resource Center in 2005 on the activities of selected state programs. The goals of the case studies are to:

- Document "promising practices."
- Identify policy issues relevant to providing services to people with Alzheimer's disease and their families.
- Identify strategies for accomplishing program goals.
- Identify implementation barriers and ways of overcoming them.
- Assess how selected sites are addressing the goals of the ADDGS program.

One of the themes of the case studies is how grantees achieve *systems change* and *sustained change*, which are two of the key priorities of the U.S. Administration on Aging for current and future grantees under the ADDGS program. At its core, these systems and sustained change case studies are about how grantees seek to change the "care environment" for people with Alzheimer's disease and their families. To improve the care environment, it is necessary that:

- The needed services exist and are maintained over time.
- Eligibility criteria for the services include people with dementia and their families.
- People with dementia or their families know that services exist, understand how the services would benefit them, and know how to locate and arrange the services or are effectively assisted with these functions (e.g., through care consultation and information and referral systems and by knowledgeable health, social service, and long-term care providers).

- Service providers are trained and knowledgeable about Alzheimer's disease and dementia care.

- The quality of the services is high enough that people with dementia and their families will accept and benefit from them.

- Funding is available for the services.

In these case studies, systems change refers to activities that result in ongoing modification in state or local government or provider practices, policies, financing, and delivery of services for people with Alzheimer's disease and their families. In Maine, for example, the model respite care program established with ADDGS funds and administered by the Area Agencies on Aging was incorporated into the state home- and community-based care system by making respite care a covered service in Medicaid and state-funded programs.

Although often hard to document, an important component of systems change is altering the "ongoing way of doing business" among providers or government officials in ways that take into account the needs of persons with Alzheimer's disease and their families. An example would be how the North Carolina Grantee established informal relationships among providers and state officials. At the local level, Family Consultants have developed and trained informal networks of providers to meet caregiver needs. At the state level, the grant leadership is working with officials from a range of departments to coordinate efforts and to develop joint policies to address caregiver concerns. Moreover, some Grant activities are supportive of and consistent with overall state efforts at systems change, but they may not alter the financing and delivery system.

Sustained change, on the other hand, refers to whether the activities funded by the project will continue after the grant ends. An example of sustained change is the continued support by Tulsa Community College (TCC) of the ADDGS-initiated Geriatric Technician training program. Sustained change can be achieved through systems change or through obtaining other sources of funding. All systems change is sustained change, but not all sustained change is systems change. Some activities are geared to particular activities or service areas by providers and do not change the overall financing and delivery system within the state.

To illuminate the issues involving systems and sustained change, Maine, North Carolina, and Oklahoma were selected for case studies.[1] North Carolina was selected for this case study because of its initiatives to create a community-based, family-centered service system that provides access to dementia-specific respite care and long-term care services. As part of the Grant, North Carolina is targeting an underserved rural, minority, and low-income elderly population.

[1] The theme of the other case studies is the use of evidence-based practices. ADDGS programs in California and Colorado were selected to illustrate those issues.

The overall goal of Project C.A.R.E. is to improve the quality and choice of and access to respite services for families in the community caring for individuals with Alzheimer's disease or related dementia. **Exhibit 1** lists the specific goals of Project C.A.R.E.

Exhibit 1. Principal Components of North Carolina's ADDGS Grant

- Integrating the needs of the family dementia caregiver into Division of Aging and Adult Services long-term care service programs and state long-term care planning.
- Exploring the efficacy of varying administrative sponsorship.
- Increasing access and availability of a comprehensive range of dementia-specific respite services by using the Family Consultant model.
- Offering consumer choice, consumer-directed respite care, and a flexible dementia caregiver program.
- Conducting outreach to rural, minority, and low-income families with dementia-specific respite care.
- Connecting families with dementia-specific training, providing informational and educational materials, and serving as a portal for families to access community resources, information, and other long-term care service options.
- Leveraging ADDGS funds to sustain the program after Grant funding ends.

Information for this case study was gathered by reviewing administrative files at the U.S. Administration on Aging and Web sites and by conducting an in-person site visit in July 2005 in Raleigh, Durham, Winston-Salem, and Charlotte, North Carolina. As part of the site visit, RTI staff interviewed Project C.A.R.E. staff at the state and local levels, state aging officials, research experts, grant partner (e.g., Area Agencies on Aging and hospice) staff, respite providers, and advocacy group representatives.

The principal findings from the North Carolina case study are listed in **Exhibit 2**.

Exhibit 2. Principal Findings from the North Carolina Case Study

- The Grant has integrated the needs of family dementia caregivers into public programs and long-term care planning. This has been accomplished through cooperative strategic planning at the state level and through the Family Consultants' efforts to build networks of agencies and providers at the local level.
- The efficacy of Project C.A.R.E. has been validated in two different settings: as a direct service of the Alzheimer's Association and as a part of a unified county social services agency.
- Project C.A.R.E. has raised the profile of the Western Carolina Alzheimer's Association Chapter and made the needs of Alzheimer's disease caregivers visible to policymakers at the state and local level in North Carolina.
- The North Carolina project has increased access and availability of a comprehensive range of dementia-specific respite services. The project has used the Family Consultant model to develop agency partnerships, recruit and train service providers, publicize the availability of caregiver services, conduct in-home assessments, facilitate the connection between the caregiver and respite care options and providers, and provide continuing case coordination.
- The Grant has expanded consumer choice and consumer-directed respite care. It has offered individualized attention and specific consumer-directed options in scheduling and staffing of respite services. At the state level, Project C.A.R.E. has worked with other agencies and grants to expand consumer-directed service options.
- Project C.A.R.E. has targeted rural, minority, and low-income families using personal contacts with organizations, including faith-based organizations, and individuals to overcome the cultural and geographical isolation facing rural mountainous communities and urban minority communities.
- The North Carolina project has connected families and providers with information and services to produce a higher quality of life for persons with Alzheimer's disease and their caregivers. It has connected caregivers to a range of other services offered by faith-based organizations, volunteer groups, social service and public safety agencies, and service groups.
- Project C.A.R.E. has leveraged ADDGS funds for sustainability through resources from private foundations and other long-term care grants and by approaching the state legislature. At the Mecklenburg County site, the program has demonstrated its value to a local agency that now includes the Family Consultant's responsibilities among its permanent functions.

BACKGROUND ON NORTH CAROLINA AND ADDGS GRANTEE

The North Carolina Division of Aging and Adult Services (the Division), part of the North Carolina Department of Health and Human Services, administers state and federal programs for older adults in North Carolina and the state's social service programs for both older and disabled adults and their families. The Division is the designated State Unit on Aging, responsible for the state aging plan and partnering with Area Agencies on Aging and county Departments of Aging to implement the plan. The Division oversees the social service programs provided by the state's 100 county departments of social services. These programs include case management, home and community-based services, institutional placement services, the State Adult Protective Services program, and guardianship services.

North Carolina began to provide support for caregivers of older adults with Alzheimer's disease in 1984 with a state legislative appropriation, totaling $200,000 annually, to create an Alzheimer's Support Program. The Division implements this program through a contractual arrangement with the state's two Alzheimer's Association chapters (the Western Carolina Chapter and the Eastern North Carolina Chapter), which each receive $75,000 annually. The Division has a technical support contract for the program with the Duke University Center for Aging Support Program, which receives $50,000 annually.

North Carolina also provides services to individuals with Alzheimer's disease through a county-based system. Each county receives funding from the State Home and Community Care Block Grant program, which consolidates funds from both state and Older American Act funds. The Division of Medical Assistance within the North Carolina Department of Health and Human Services operates a Medicaid home and community-based services waiver program, the Community Alternatives Program for Disabled Adults, which offers an array of services, including adult day services. Divisional staff report that funding for this service is limited, waiting lists for in-home services are long, and the state has the most restrictive income and resource limitations in the United States. As a result, access is limited to the very poor, those with no savings, and those with little or no Social Security work history.

North Carolina has received three ADDGS Grants. The state received its first ADDGS Grant in 1993 and used those funds through June 2000 to develop state group respite standards and to establish a community-based group respite program. With that funding, the state created group respite services using existing senior centers as locations to reach people in rural and underserved areas. In 2001, a second ADDGS Grant allowed the state to introduce the first pilot version of Project C.A.R.E. The current Project C.A.R.E. Grant builds on that grant. It offers families an individualized approach to respite care with in-home assessment and care planning, some respite funding with a wide degree of flexibility and choice, and education and training for caregivers.

The key elements of Project C.A.R.E. are the:

- Use of a Family Consultant model.
- Delivery of dementia-specific respite care using both public and private entities.

The Family Consultant is trained in dementia caregiving issues and supported by dementia and social work experts. The Family Consultant conducts outreach to the community through presentations and visits to support groups, health fairs, and educational events and to individuals through in-home assessments. In the home, the Family Consultant directly assists family caregivers through counseling and assessing the caregiver's needs, advising the caregiver about options for support, bringing the caregiver into contact with appropriate service providers, and monitoring the quality of respite care. The Family Consultant also administers the funds the project provides to families for respite care.

The Family Consultant develops dementia-specific respite care by working with private service providers, public service organizations, faith-based groups, and governmental agencies to promote the development of dementia-specific care support. The Family Consultant makes potential providers aware of the demand for their services. The Family Consultant organizes respite care training opportunities in cooperation with Alzheimer's Association staff. By developing a pool of potential new consumers, the Family Consultant gives providers an incentive to train their workers on the needs of dementia caregivers.

Project C.A.R.E. is now based in three sites in North Carolina, compared to two sites under the previous Project C.A.R.E. ADDGS Grant from 2001 to 2004. Two of the sites continue from the previous grant project: a site based in Asheville serves six isolated rural western counties (an increase of two counties from the previous project grant) and a site based in Winston-Salem serves urban Forsyth County and two adjacent rural counties (an increase of one rural county from the previous project grant). The third site, based in Charlotte, was a comparison site under the previous project grant and now provides full Project C.A.R.E. services to urban Mecklenburg County. The Western Carolina Alzheimer's Association Chapter employs the Family Consultants for the Asheville and Winston-Salem sites, while the Mecklenburg County Department of Social Services provides the Family Consultant in that site, with support from the local office of the Alzheimer's Chapter.

The primary partners for both the current and earlier Project C.A.R.E. grant are the following:

The Western Carolina Chapter of the Alzheimer's Association, (the Chapter), which has been in operation for 22 years and now covers 49 of the state's 100 counties. The Chapter serves as an advocate for individuals with dementia and provides information, education, and training to family and professional caregivers. The Chapter employs and supports two full-time Family Consultants, one based in Asheville and the other based in Winston-Salem. The Chapter office in Charlotte also supports the Mecklenburg County Department of Social Services Family Consultant in implementing Project C.A.R.E. in that county.

The Mecklenburg County Department of Social Services, whose Services for Adults Division is responsible for providing human services, transportation, senior nutrition, adult social work, and Medicaid services to adult county residents. The Department is active in outreach to older adults through its centralized county information and assistance program, "Just 1 Call," and the Status of Seniors Initiative, a community-wide strategic planning process seeking to create a "senior-friendly" community. The Department also is responsible for local administration of the National Family Caregiver Support Program in the county under the oversight of the local Area

Agency on Aging. The Department employs the Project C.A.R.E. Family Consultant for the county who also works as a Family Caregiver Support Specialist. The Family Consultant concentrates on community outreach and caregiver education and is a program mentor to social workers in the Department's Services for Adults Division.

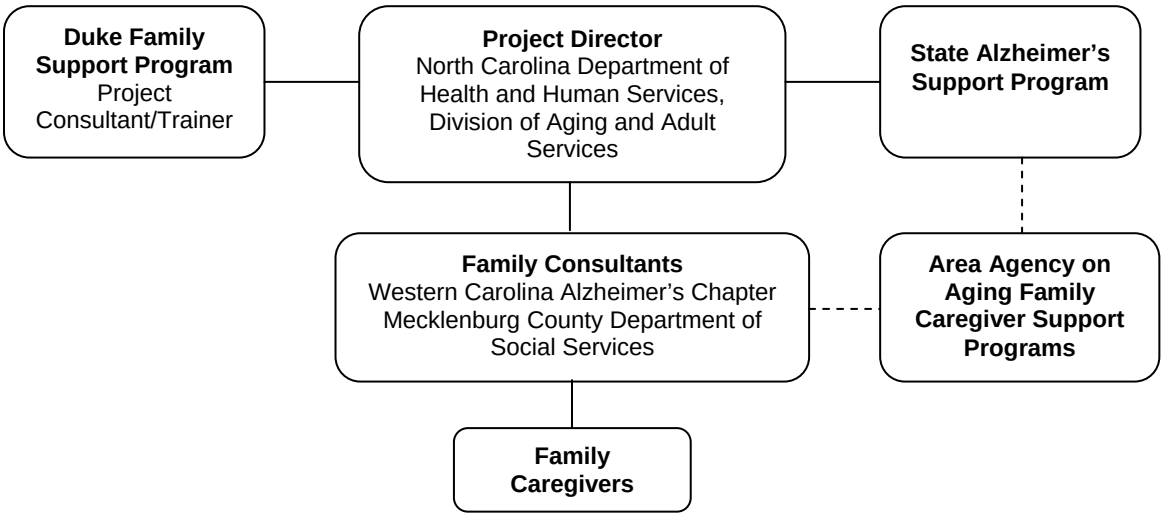
The Duke University Center for Aging Family Support Program, which has been providing dementia-specific training and technical assistance for the state since 1984. In addition to Project C.A.R.E., the Duke University program works with the National Family Caregiver Support Program and the State Alzheimer's Support Program. The Center provides training and technical assistance and assists in developing and reviewing grant-generated educational and policy products.

The State Alzheimer's Support Program, which provides funding to the state's two Alzheimer's Association chapters for services to Alzheimer's families, and to the Duke University Center for Aging Support Program for technical support of their efforts. The program collaborates with Project C.A.R.E. at the state level in support of Alzheimer's services.

The Area Agencies on Aging for Regions B, C, F, and I, which administer Older American Act services in the counties being served by Project C.A.R.E. The Family Caregiver Support Program is assisting the Project C.A.R.E. Family Consultants with outreach, assessment, community training and volunteer initiatives, and development of an inventory of resources. The Family Caregiver Resource Specialists also are identifying and referring families in need of dementia-specific respite care to Project C.A.R.E.

The organizational relationships among the partners are depicted in **Exhibit 3**. (Solid lines show a formal reporting relationship and dotted lines an informal consultative relationship.)

Exhibit 3. Project C.A.R.E. Key Partners



GRANT STRATEGIES AND ACTIVITIES TO ACHIEVE SYSTEMS AND SUSTAINED CHANGE

The Grant has used a variety of strategies and activities to achieve systems and sustained change for people with dementia. These strategies are described below.

Integrating the Needs of Dementia Family Caregivers into Public Programs and Long-Term Care Planning

State officials report that Project C.A.R.E. is increasing awareness and knowledge about caregiver needs and preferences within the North Carolina Department of Health and Human Services. Working with the Long Term Care Cabinet, the U.S. Administration on Aging-funded National Family Caregiver Support Program, and the state-funded Alzheimer's Support Program, Project C.A.R.E. is helping to change state long-term care services to incorporate the needs and preferences of the family caregiver in addition to those of the person with disabilities.

The State Long Term Care Cabinet, sponsored by the Office of Long-Term Care, includes the Directors of Divisions and Offices of the Department of Health and Human Services with responsibility for long-term care services. Through its representatives on the Cabinet, Project C.A.R.E. is part of the planning process for the Department of Health and Human Services that addresses special long-term care issues that cut across departmental divisions and offices and makes recommendations to the Secretary of Health and Human Services. Project C.A.R.E. staff participate on and make presentations to workgroups of the Cabinet in support of services to dementia caregivers.

Project C.A.R.E. works with the National Family Caregiver Support Program at the state and local levels. At the state level, leaders of the two programs jointly plan to meet caregiver needs and maintain legislative support for caregiver services. At the local level, the Family Consultants work in close cooperation with regional and county Family Caregiver Program Resource Specialists. The North Carolina Family Caregiver Support Program does not have a dementia-specific component, and the two programs provide referrals to each other, linking dementia caregivers to Project C.A.R.E. and giving the Family Consultants a source of support for nondementia caregivers they encounter. The North Carolina Family Caregiver Support Program provided almost $90,000 for fiscal years 2002-2004 to Project C.A.R.E. for respite services in rural mountain counties. The two programs also conduct joint provider training.

Project C.A.R.E. is also particularly involved with the state-funded Alzheimer's Support Program. The funding for the Alzheimer's Support Program is counted as part of the state matching funding for the ADDGS Grant. This circumstance protected the program in 2002, when the state legislature considered ending the program as a cost-cutting measure. Because doing so would have ended Project C.A.R.E. as well, the Division and the Alzheimer's Association chapters were able to convince the legislature to maintain the program.

Exploring the Efficacy of Varying Administrative Sponsorship

Project C.A.R.E. is piloting two service models that differ by type of organization administering the project. One method uses a private entity, the Western Carolina Chapter of the Alzheimer's Association, and the other method uses a public entity, the Mecklenburg County

Department of Social Services. Both methods have been successful at bringing the Alzheimer's Association resources to underserved populations and at tailoring the project to regional strengths and needs (Martin et al., 2005).

Western Carolina Chapter

As implemented by the Chapter, Project C.A.R.E. provides a direct link between dementia caregivers and the expertise of the Alzheimer's Association. The Chapter administers Project C.A.R.E. through two full-time Family Consultants working out of area offices in Asheville and Winston-Salem. **Appendix 1** illustrates the service areas of these two offices in North Carolina. As Chapter employees, the Family Consultants spread an awareness of the Chapter's range of activities to the public and to the network of government and provider agencies serving dementia caregivers. Within this cooperative framework, the Chapter is able to provide outreach, education, and training to the cooperating agencies, enhancing their knowledge of dementia and dementia caretaking issues.

The implementation of Project C.A.R.E. through the Western Carolina Chapter has changed the role of the Chapter in serving dementia caregivers and persons with Alzheimer's disease. Prior to the 2001 Grant project, the Chapter (then divided into two chapters, the Western North Carolina Chapter based in Asheville and the Carolina Piedmont Chapter based in Charlotte) had ceased offering any in-home services and had become primarily a provider of educational and outreach programs. The Asheville-based predecessor chapter had provided a one-time grant of $500 for respite to families who requested it, but neither of the predecessor chapters was coordinating services to families by the time they merged in 2001. Now, however, the Western Carolina Chapter is a central agency in the coordination of local dementia caregiver services in both regions.

Project C.A.R.E. has enhanced the relationships between the Chapter and its partners in the Grant and the national Alzheimer's Association. The Division also has developed a much closer relationship with the Chapter, and both organizations express increased satisfaction with their working relationship. The Chapter has also gained a close relationship with the Area Agencies on Aging in the Project C.A.R.E. service area and with the Mecklenburg County Department of Social Services (Charlotte headquarters) in providing expertise on Alzheimer's disease and related disorders. The national Alzheimer's Association policy office has expressed interest in Project C.A.R.E., and the Chapter was honored at the national Alzheimer's Association 2005 Dementia Care Conference with a National Program Clearinghouse Award. The Chapter has built productive relationships with community service providers, who are increasingly participating in Chapter workshops and classes and hosting support groups and other activities.

Mecklenburg County Department of Social Services

In Mecklenburg County, the Family Consultant funding and function reside with the Department of Social Services, a comprehensive social service agency for the county. Also in Mecklenburg County, the National Family Caregiver Support Program is administered by county-level staff in consultation with the Regional Family Caregiver Resource Specialist at the Area Agency on Aging. Thus, in Mecklenburg County, the regular Home and Community Care

Block Grant program, the National Family Caregiver Support Program, and Project C.A.R.E. all operate within the same agency. The Charlotte office of the Western Carolina Alzheimer's Association Chapter supports Project C.A.R.E. by providing dementia expertise, education materials, and training for the Family Consultant and other involved agency staff members.

Under the 2001 ADDGS Grant, a case manager in Mecklenburg County provided counseling, needs assessment, and respite services, including funds for dementia respite, but without a dementia focus as a comparison to the work being done in the other service areas of Project C.A.R.E. Mecklenburg County was designated a regular service area of the project under the current Grant, and the Department expanded the role of Project C.A.R.E. by assigning its 20 social workers in the Department's Services for Adults Division to conduct in-home visits to connect caregivers to Project C.A.R.E. and other resources as part of their case management duties. Supported by training from the Chapter and directed on the Project C.A.R.E. approach by the Family Consultant, each staff member implements Project C.A.R.E. with dementia caregivers they encounter in their duties. Intake staff screen applicants for service for potential eligibility for Project C.A.R.E. as a part of the standardized departmental assessment used in their initial contacts with clients. The Family Consultant, who is phasing out of direct service, is increasing outreach activities, both in identifying and referring families for services and in making educational presentations to the general community.

Project C.A.R.E. has been beneficial to the Department of Social Services by providing additional training and resources. The Department has also sent representatives to Alzheimer's conferences both in Charlotte and at Duke University. The Grant funding has also helped the departmental staff extend services by providing additional funding for services to dementia caregivers. Home and Community Care Block Grant program funding for adult services in the county last year was fully committed a month and a half after the beginning of the fiscal year; the availability of Project C.A.R.E. respite funds for dementia caregivers provided an ongoing source of support for this population. Project C.A.R.E. funding and the Family Caregiver Support Program are among the few sources of support that the department has to offer to caregivers after Home and Community Block Grant funds are depleted.

In the Mecklenburg County site, the Charlotte office of the Western Carolina Alzheimer's Association Chapter acts in a consulting role to the Family Consultant and the Department of Social Services. Instead of linking to a network of agencies, the Chapter is forging links with a Department that brings all those agency functions together in one organization. In this setting, the Chapter has the opportunity to support the Department's organizational effort to reach dementia caregivers by providing expertise and educational resources to Department staff.

Increasing Access to a Comprehensive Range of Respite Services Using the Family Consultant Model

The Family Consultant increases access to dementia-specific respite services for dementia caregivers in five ways:

- Personalized assessment.

- Simplified eligibility.
- Financial support.
- Ongoing case management.
- Provider development.

The in-home assessment is a key element in this process, giving the Family Consultant the opportunity to become intimately aware of the caregiver's situation and needs. By being present in the home, the Family Consultant can gain the trust of the caregiver, provide the caregiver with the opportunity to discuss needs in a secure setting, and observe the interactions of the caregiver with the person with dementia and other family members. With this level of knowledge, the Family Consultant is able to guide the caregiver to the respite services that best respond to those needs.

Coupled with the personalized approach of the in-home assessment is the Project C.A.R.E. structural orientation toward ease of eligibility determination and initiation of services. There is no means test for Project C.A.R.E., which spares the caregiver a potentially lengthy application. Eligible families are those in which:

- An individual has been diagnosed with Alzheimer's disease or a related dementia.
- The individual with dementia resides in a county served by the program.
- The individual is not receiving Medicaid Community Alternative Program services.

Once an eligible individual is identified, the Family Consultant can offer funding that the caregiver may use to purchase respite services. Caregivers are eligible to receive an annual stipend for respite from the grant, once up to $2,500 per year but now reduced to $1,800 in the Asheville and Winston-Salem areas and $2,000 in Mecklenburg County. The amount was reduced to provide funding to more families. This funding, which is paid directly to the vendor of the caregiver's choice, gives the family the opportunity to use respite care and become familiar with the local respite provider network. There is no co-pay requirement for families, although they are given the opportunity to voluntarily contribute to Project C.A.R.E. based on a sliding scale formula.

Family Consultants report that the project is not able to provide funding to every family it serves at the time of initial assessment. In the Asheville and Winston-Salem areas, there has been a waiting list of up to 190 families. Those Family Consultants report, however, that families generally wait no more than 3 months to receive funding, and that families receive counseling, consultation, training, and other support services even when respite funds are not available. The Mecklenburg County Family Consultant also reports that families may experience a delay in receiving Project C.A.R.E. respite support until additional funding comes at the beginning of a fiscal year. The average length of Project C.A.R.E. service use is approximately 8 to 10 months with one-third of client families re-enrolling annually. The caseload turnover is about two-thirds

annually, most often due to the client becoming eligible for Medicaid waiver support, passing away, or entering a nursing home.

The Family Consultant provides an ongoing case management/care planning function for the caregiver. The Family Consultant establishes a continuing relationship with the caregiver, monitoring the family situation and assessing whether the services in place are continuing to meet the caregiver's needs as the family situation changes. The Family Consultant maintains an ongoing relationship with the provider agencies serving the families and is available to assist if issues concerning quality or appropriateness of care. The Family Consultant also links families to other resources, such as Powerful Tools for Caregiving self-care classes, local support teams, Faith In Action groups, and the Alzheimer's Association's Safe Return program.

Finally, the Family Consultant encourages local respite care providers to expand their capacity and expertise. The Family Consultant provides referrals for service to qualified agencies, and the respite funding is an important source of income for these providers. Typically, these service providers assess many families with a need for respite care but no means to pay for it, while the provider has excess capacity but no way to subsidize the respite need. Project C.A.R.E. subsidies bridge the gap, enabling the agencies to serve the families. One technique for encouraging caregivers and clients to try respite care is a program called "Memory Camp," provided by Project C.A.R.E. funds. Working with cooperating adult day services providers, the Family Consultant can give free 3-day passes to family caregivers that allow them to bring their family members with dementia to the adult day services center. Often when families try these "Memory Camps" they find that both they and their family member with dementia enjoy the experience and are willing to accept the Project C.A.R.E. respite support.

Offering Consumer Choice and Consumer-Directed Respite Care

The introduction of consumer choice and consumer-directed services to support dementia caregivers is an important feature of the current Project C.A.R.E. Grant project. At the local level, family caregivers have the choice of using Grant respite funding to select in-home, overnight respite, and congregate care (adult day services and group respite). In the four rural counties added to Project C.A.R.E.'s service area under the current Grant, families have a consumer-directed option of hiring respite workers directly rather than using agency-directed services. Families have flexibility in scheduling, including the ability to use care sporadically rather than at a regular established time and the ability to schedule care in the evenings and on weekends rather than during standard business hours. Family caregivers also have the ability to budget the Project C.A.R.E. respite funding across the entire year rather than on a weekly or monthly basis. The Family Consultants work with providers regarding service issues if a family is not satisfied and connect families with other providers if needed.

The option of hiring a worker privately, introduced in anticipation of a lack of service providers in some rural areas, has been used only occasionally thus far. Grant staff members believe that this may be because families are concerned about the absence of liability protection for privately hired support or because this approach is less needed as service providers have expanded services.

Incorporating Project C.A.R.E.'s flexibility into the Mecklenburg County Department of Social Services setting accustomed to tightly regulated programs has been a challenge. The County Department overcame the barrier of managing funds in a flexible manner through the practical step of having staff from the departmental accounting department meet with State Division of Aging and Adult Services finance staff. Armed with a technical understanding of the issues and appropriate accounting procedures relating to flexible funding under the Grant, the County Department accounting staff was able to smoothly integrate project finances into the Departmental system. Now that the County Department has seen how this flexibility works in practice, it has extended it to some degree into its own social service programs.

Project C.A.R.E. also works to promote consumer direction at the state level in collaboration with a number of other grant efforts in the state. State staff believe that input from Project C.A.R.E. is helping state officials evaluate options for increasing consumer choice and consumer-directed care. In particular, Project C.A.R.E. is working with the Office of Long-Term Care, grantee for a U.S. Centers for Medicare & Medicaid Services-funded Real Choice Systems Change grant and grantee with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services for the North Carolina Community-Integrated Personal Assistance Services and Supports (CPASS) Initiative. This project is focusing on creating state regulations supportive of consumer direction, joint development of resource materials, and direct care workforce recruitment and retention. Leaders of both CPASS and the consumer-directed component of the Real Choice Systems Change grant also cooperate regularly with the Project C.A.R.E. grant leadership by sharing information, training, and educational materials.

Project C.A.R.E. is also promoting consumer direction through contacts with other grants and groups. Project C.A.R.E. is working with leaders of the Aging and Disability Resource Center (ADRC), a grant project jointly funded by the U.S. Centers for Medicare & Medicaid Services and the U.S. Administration on Aging. The ADRC will provide a central source for aging and disability information, and Project C.A.R.E. will provide training for staff and volunteers on dementia-specific respite and caregiving information. The state Direct Care Workers Association, developed by the Real Choice Grant, keeps its membership aware of the Project C.A.R.E. effort to introduce consumer choice and works with Project C.A.R.E. leadership to increase the training and education opportunities for direct service workers. At the time of the site visit, the state had submitted a Real Choice Systems Transformation grant application, which would facilitate increased cooperation between all the grantees in their local efforts.

Providing Outreach to Rural, Minority, and Low-Income Families

The Project C.A.R.E. sites specifically target three underserved populations: the low-income, mostly Caucasian, rural, population of the mountain counties; the low-income, minority population of two urban areas (Mecklenburg County [Charlotte] and Forsyth County [Winston-Salem]); and the low-income, mostly Caucasian, rural, population near the North Carolina-Virginia border (Surry and Stokes counties). While different in many ways, these populations share a common characteristic—insular communities that are economically, culturally, or geographically isolated and lack access to dementia-specific respite care and other caregiver services.

In establishing the trust level that makes it possible for Family Consultants to work with this population, the Family Consultants begin by establishing relationships with trusted community institutions. In Winston-Salem, for instance, the Family Consultant made a connection with a ministerial roundtable within the African American community, presenting an overview of Alzheimer's disease, its impact on the African American community, and available care and support. In response, the roundtable members publicized Project C.A.R.E. in their congregations and arranged for the Family Consultant to speak to the congregations before Sunday services, and they also publicized the project to women's fellowship and missionary groups. In the mountainous counties around Asheville, the faith community has also been helpful in reaching this population. For example, the Family Consultant there is working with a large congregation through its 40 deacons. After a presentation about Alzheimer's disease and Project C.A.R.E., the deacons, each of whom was responsible for church members in a geographic area, publicized the project and encouraged congregational caregivers to seek support through Project C.A.R.E. Because of the level of service Family Consultants provide, they have gained acceptance in the targeted communities through word-of-mouth endorsement.

The outreach situation for Stokes and Surry counties is complicated by the fact that these predominately white and rural counties are part of the same site as the adjoining urban and largely African American Forsyth County. Under the first Project C.A.R.E. from 2001 to 2004, the Family Consultant had been doing outreach only in Forsyth County. The Family Consultant therefore had to develop a different approach to reaching families in these two rural counties. Working with the Family Caregiver Resource Specialist from the Area Agency on Aging, the Family Consultant introduced Project C.A.R.E. through a presentation at Stokes County's primary senior center. With this introduction, the Family Consultant has been able to contact and support families in the county. Outreach in adjoining Surry County began in July 2005 with the Family Consultant approaching community leaders and service providers to develop outreach methods suited to the population. This Family Consultant also has successfully pursued media exposure. In Winston-Salem, connections with the ministerial roundtable resulted in the Family Consultant appearing on a minister's radio show on two consecutive days, resulting in numerous inquiries. The Family Consultant also appeared in a local access television show, and contact information for Project C.A.R.E. has been displayed by the station in its announcement line.

Connecting Families with Information and Services

Project C.A.R.E. uses its close relationship with the Alzheimer's Association and the Duke Family Support Program to make dementia-specific resources available to both caregivers and provider agencies. Family Consultants educate caregivers on an in-person basis through the in-home assessment process.

Working in cooperation with Alzheimer's Association staff, the Family Consultants offer group educational sessions for caregivers, provider agencies, and volunteers. These sessions include training on the nature of Alzheimer's disease and related disorders, communication skills for working with people with these diseases, techniques for managing behavioral issues that often accompany the disease, and techniques for providing personal care. For providers, other sessions cover practical issues in dementia care, such as making referrals, assessing family needs, selecting appropriate respite services, and procuring payment for services from state and county programs and agencies. This training has the potential to help caregivers better manage

interactions with their family member with dementia, contributing to reduced stress and a higher quality of life. The training also is designed to improve the quality of care offered by provider agencies to persons with dementia, making respite a more acceptable option for caregivers.

The Family Consultants also cooperate with representatives of other programs serving caregivers, most notably Family Caregiver Resource Specialists from the Area Agencies on Aging, in conducting joint training presentations. In addition to conducting general presentations for caregiving families and respite providers about their programs, their joint efforts include the presentation of the Mather LifeWays training course "Powerful Tools for Caregiving," which teaches caregiver skills and addresses issues such as self-care, stress management, and coping skills.

The Duke Family Support Program has also been an important source of educational information for Project C.A.R.E., producing a number of publications and other printed materials in cooperation with the grants the Family Consultants make available to caregivers. These publications are listed in **Exhibit 4**.

Exhibit 4. Publications for Project C.A.R.E. from the Duke Family Support Program

- "You Are One of Us," a guide to helping faith-based congregations connect with Alzheimer's families (Gwyther, 1995).
- Visiting tips and a sample letter that families could adapt to send to their congregation friends explaining that a family member has Alzheimer's disease.
- A guide for caregivers in dealing with feelings of anger, "Pressure Points—Alzheimer's and Anger" (Ballard, Gwyther, and Toal, 2000).
- A pamphlet titled "Wait a Minute—When Anger Gets Too Much." Based on "Pressure Points" and developed in cooperation with the Winston-Salem-based Family Consultant, it offers simple straightforward advice. The flyer was printed on waterproof stock to make it sturdy and encourage caregivers to keep it handy on the counter or on the refrigerator door to guide them in emergencies.
- "Working with Family Caregivers of People with Memory Disorders," a North Carolina information and assistance toolkit for training county aging providers to work with family dementia caregivers (Gwyther and Ballard, 2002).

Project C.A.R.E. also serves as a portal for families to access locally based community resources, information, and other long-term care services. Family Consultants connect families to local services such as hospice and volunteer service groups. Family Consultants particularly reported working closely with local hospice organizations that often become involved with caregiver families experiencing end-stage Alzheimer's disease. With their common interest in the support of caregivers, the two programs cooperate so that families have the advantage of both resources. One particularly valuable hospice service is professional counseling for caregivers. Family Consultants also work with other kinds of volunteer groups such as faith communities, which provide housing modifications and repairs, food, and temporary funding for utilities. An important partner in Charlotte is Love, Inc., a faith-based organization with a membership of 160

congregations from 23 denominations and 1,500 to 2,000 volunteers. The organization provides services such as ramps for houses and operates an Adopt an Elder program that links volunteers with older persons to help with household chores.

The Family Consultants also have developed ties with public service agencies in the counties, for instance, publicizing such benefits as free cooling fans when these are made available by local senior services agencies or consulting with the local police. Family Consultants also help families to access benefits such as the $1,200 per year benefit for prescription medications available to elderly families from the state tobacco settlement fund. Many dementia medications are quite expensive, making this a very valuable service.

Appendixes 2 and 3 contain tables of the services the Grants have provided, including gender and race, for the prior Grant and for the first year of the current Grant, respectively.

Leveraging ADDGS Funds for Sustained Change

A key issue for Project C.A.R.E. is how to continue and expand funding. The Division is very interested in piloting Project C.A.R.E. in select eastern North Carolina counties to demonstrate its applicability statewide. In addition to maintaining the current models of Project C.A.R.E., the Division wants to demonstrate a third service administrative structure in which the Family Consultant would be based in a different community-based organization such as an Area Agency on Aging. The Duke Family Support Program asserts that North Carolina is strategically placed to create a seamless, coordinated dementia-capable system of family-centered, caregiver-focused long-term care services that can be replicated in other states (Martin et al., 2005).

The placement of the Family Consultant within the Department of Social Services in Mecklenburg County has potential for sustaining a higher level of service to dementia caregivers than existed prior to Project C.A.R.E. The Family Consultant is a regular employee of the Department of Social Services, reserving Project C.A.R.E. grant funding exclusively for dementia-specific respite care. Additionally, training by the Charlotte Chapter of the Alzheimer's Association and Duke Family Support Program is given to adult services and intake staff members in the Department, disseminating the knowledge throughout the organization and further enhancing the Department's organizational competency in dementia caregiving issues. Although the Department may not be able to provide the same level of dementia-specific respite funding in the absence of grant support, the intake referral process and institutional knowledge of the issues would still provide dementia caregivers with a higher level of service than existed prior to Project C.A.R.E.

In the other two project sites, where the Family Consultant is an employee of the Alzheimer's Association Chapter, it is less clear that the Family Consultant function could be maintained in the absence of ADDGS funding. The Chapter primarily depends on grants from the state and federal government and private contributions to fund its budget. The Chapter has had some success in securing foundation support to pay the salaries of the Family Consultant. They have received grants from the Kate B. Reynolds Foundation for $150,000 for fiscal years 2004-2006 and the Sisters of Mercy for $92,000 in fiscal years 2005 and 2006. Without additional funding, Chapter officials are uncertain of their ability to continue the respite service component of Project C.A.R.E. at the conclusion of the current Grant.

The Division is working in cooperation with the Western Carolina Alzheimer's Association Chapter to develop a strategy for continuing the project, and divisional and grant leaders foresee four possible approaches:

- Applying for support from private foundations to expand Project C.A.R.E. to eastern North Carolina. Divisional and grant leaders agree that this may prove useful but that ongoing continuation will require a steady stream of governmental funding.

- Approaching the legislature for budgetary appropriations for dementia-specific respite services by the counties. The state already supports respite care under the Home and Community Care Block Grant, but there is no separate appropriation for dementia-specific respite services under this block grant program. A drawback to this approach is that, even if there were a separate appropriation, county-level appropriations would require the Alzheimer's Association chapters to advocate in each county for dementia-specific respite services be one of the funded block grant services and to become an approved provider of those services. In the case of the Western Carolina Chapter, a county-based program would involve them in 49 sets of negotiations with separate and uniquely organized county governments. Another approach under discussion would include future dementia caregiver support as a separate program associated with the National Family Caregiver Support Program and funded jointly by the state. Division leaders have not yet developed a proposal detailing how this could be structured.

- Collaborating with the State's Real Choice Systems Change Grant to expand Project C.A.R.E. to eastern North Carolina. Division staff members and leaders of the grant have informally discussed using some of the grant funding for this purpose.

- Supporting the development of federal legislation to give states continuation funds through the ADDGS program. Under that circumstance, Divisional leaders indicated they would seek to leverage those funds to gain state funding to continue Project C.A.R.E. in the western part of the state and to expand to the eastern part of the state.

In support of these sustainability strategies, the Grantee is working to conduct research and evaluation activities for the Grant, using Division resources and relationships with local universities. A recent article in the *North Carolina Medical Journal* describes Project C.A.R.E. and discusses its role in providing dementia-specific respite (Derence, 2005). Two postdoctoral fellows and their advisors at the University of North Carolina's Institute on Aging are exploring future directions for Project C.A.R.E., which include the possible expansion of the program to the eastern part of the state. The Division is providing a small stipend of $2,500 from grant funds to support this study, the results of which will be submitted to the *Journal of Applied Gerontology*, a publication that is widely read in the southeastern policy and practice community. The Duke Family Support Program and the Division prepared a policy paper that describes the Project C.A.R.E. delivery of dementia-specific respite services and discusses lessons learned through the previous grant (Martin et al., 2005). The Division also has a contractual arrangement with the Center for Aging Research and Education Support at the University of North Carolina to examine selected programs and is considering having the Center conduct a formal evaluation of the current Project C.A.R.E. Grant in its third year.

CONCLUSION

Project C.A.R.E. offers families a personalized approach to respite care based on an in-home assessment and care planning, a wide degree of flexibility and choice in using respite funding, and dementia-specific education and training for caregivers. In both public and private administrative settings, Family Consultants have successfully brought personalized and flexible supports and resources to caregivers. They have developed networks of provider agencies to provide quality dementia-specific respite services, as well as networks of governmental and volunteer agencies to jointly serve dementia caregivers. Family Consultants have also provided a connection for caregivers to other community resources.

To achieve systems change, Project C.A.R.E. used a number of strategies:

- Integrating the needs of family dementia caregivers into public programs and long-term care planning. Through Project C.A.R.E., North Carolina has made a commitment to providing integrated services to dementia caregivers, moving forward the Division's belief that serving family caregivers as well as persons with disabilities is appropriate and feasible. Both in terms of cooperation in strategic planning at the state level and in the role of the Family Consultant in building networks of agencies and providers at the local level, Project C.A.R.E. brings together all available resources to make them available to the caregiver in a single package.

- Exploring the efficacy of varying administrative sponsorship. Project C.A.R.E. has demonstrated its effectiveness in two different settings. Under the guidance of the Alzheimer's Association, Project C.A.R.E. demonstrated the ability of the Family Consultant to coordinate with both local and regional groups to organize and deliver care to Alzheimer's caregivers. As a part of a unified county social services agency, Project C.A.R.E. demonstrated that it can harness the resources of a public agency and integrate the dementia caregiver support in the operations of a county social services agency, connecting Alzheimer's caregivers to a wide array of services while maintaining the flexibility that makes it effective.

  At an institutional level, Project C.A.R.E. raised the profile of the Alzheimer's Association Chapter and made the needs of Alzheimer's disease caregivers visible to policy makers at the state and local levels in North Carolina. The Division, the Area Agencies on Aging, and county and city governments have raised the priority of the needs of Alzheimer's disease caregivers and rely on the Alzheimer's Association Chapter for guidance in matters related to Alzheimer's disease.

- Increasing access and availability of a comprehensive range and type of dementia-specific respite services by using the Family Consultant model. Access is one of the key goals of Project C.A.R.E. and is expressed in the range of the Family Consultant functions: developing agency partnerships to offer a range of dementia-specific respite services, recruiting and training service providers to provide quality respite care, publicizing the availability of other caregiver services, conducting in-home assessments with the caregiver, facilitating the connection between the caregiver and

respite care options and providers, and continuing a case coordination relationship with both caregiver and provider to monitor the caregiver's satisfaction with services.

- Offering consumer choice and consumer-directed respite care. Project C.A.R.E. is committed to flexibility in meeting the caregiver's needs, both in terms of the individualized attention provided by the in-home assessment and the respite options available for the caregiver. The current grant extends this commitment with specific consumer-directed elements in the new service areas, granting caregivers multiple options in scheduling and staffing of respite services. At the state level, Project C.A.R.E. works with other agencies and grants to expand consumer-directed services.

- Outreach to rural, minority, and low-income families. The data in the appendices illustrate the effectiveness of Project C.A.R.E. in the intensive and time-consuming effort of targeting underserved populations. By making personal contacts with the organizations and individuals in these communities, the Family Consultants have taken the resources of the Alzheimer's Association and the project to individuals who would otherwise not have known about them. Family Consultants have helped overcome some of the cultural and geographical isolation facing rural mountainous communities and urban minority communities.

- Connecting families with information and services. The network development work of the Project C.A.R.E. Family Consultants also puts them and the project in a unique position to link caregivers to a wide range of long-term care services and supports beyond the Grant resources. Faith-based organizations, volunteer groups, social service and public safety agencies, and service groups all provide services that can be of value to Alzheimer's caregivers. The Family Consultant is able to make caregivers aware of these services and to make the contacts needed to bring the services to the caregivers. Project C.A.R.E. has demonstrated that it can transfer the expertise of the Alzheimer's Association into the community arena, educating both caregivers and providers on techniques that produce a higher quality of life for both the person with Alzheimer's disease and the caregiver. The project also incorporates other useful techniques into its training and resource offerings, including the "Powerful Tools" training.

- Leveraging ADDGS funds for sustainability. While it is difficult in the state's economic climate to introduce and sustain new governmental programs, the Division and the Chapter have made a diligent effort to identify resources to sustain Project C.A.R.E. Efforts are being made to engage private foundations in this need, to collaborate with other long-term care grants, and to approach state legislative staff with evidence of the project's effectiveness. The Mecklenburg County site also provides a potential template for sustainability; the program has demonstrated its value to a local agency that is willing to support the Family Consultant function and be an advocate for county-level respite funding.

Project C.A.R.E. has piloted replicable methods for delivering dementia-specific respite services and a model for bringing caregiver resources to family caregivers of persons with Alzheimer's disease and other dementias. The project has incorporated flexibility in developing and delivering resources to meet the needs of caregivers in different economic, cultural, and geographic settings.

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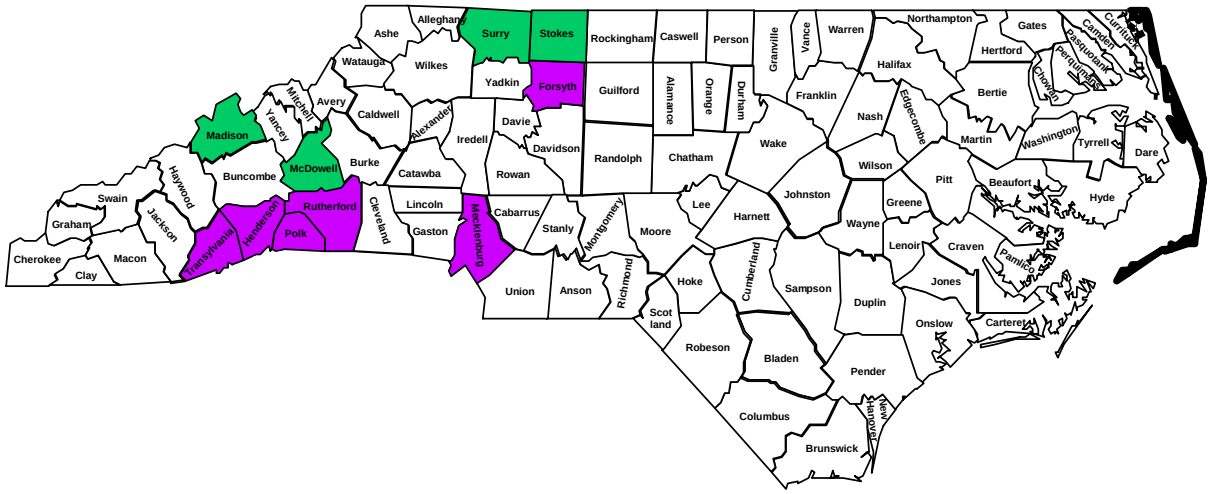
APPENDICES

APPENDIX 1

Project C.A.R.E. Site Map



The counties colored purple were included in the first Project C.A.R.E. grant from 2001-2004. The counties colored green were added for the current Project C.A.R.E. grant, 2004-2007.

APPENDIX 2. Project C.A.R.E. Enrollment and Utilization, July 2001-June 2004

PROJECT C.A.R.E. DATA: 10/01 – 7/04	Four-County Region	Forsyth County	Totals
Enrollments			
Year 1	**86**	**70**	**156**
Families "rolled over" from Year 1 to Year 2	52	50	**102**
New families enrolled Year 2	15	23	**38**
Year 2 Total	**67**	**73**	**140**
Families "rolled over" from Year 2 to Year 3	30	28	**58**
New families enrolled Year 3	47	53	**100**
Year 3 Total	**77**	**81**	**158**
Total nonduplicated enrollment	148	146	**294**
(Families "rolled over" from Year 1 to Year 3)	2	6	**8**
Nonenrolled			
Consultation, referral, information	160	83	**243**
Provider Agencies (by Type)			
In-home providers	24	18	**42**
Adult day providers	4	2	**6**
Overnight providers	7	3	**10**
Total provider agencies used	**35**	**23**	**58**
Service Use (Year 1+ Year 2+ Year 3)			
Families receiving in-home service	89	64	**153**
Families receiving adult day service	45	63	**108**
Families receiving residential overnight	5	7	**12**
No agency selected at this time	9	12	**21**
Totals	**148**	**146**	**294**
Client Gender			
Male	63	42	**105**
Female	85	104	**189**
Totals	**148**	**146**	**294**
Client Race			
African American	12	96	**108**
White	136	49	**185**
Native American	0	1	**1**
Totals	**148**	**146**	**294**

Note: From 2001–2004, the Mecklenburg County site was a "control" site for Project C.A.R.E. While funding was provided for dementia respite, the funding was administered through the county Department of Social Services without a dementia awareness focus. During 2001–2004, a total of 144 families received Project C.A.R.E. funding for respite services. In Mecklenburg County, 74 percent of client families selected adult day services and 26 percent used in-home aide services. None of the clients chose residential respite care.

APPENDIX 3. Project C.A.R.E. Enrollment and Utilization, July 2004-June 2005

PROJECT C.A.R.E. DATA SUMMARY

Annual Report for 7/1/04 and 6/30/05

Project C.A.R.E. Service Areas	Six-County Region	Forsyth & Stokes Counties	Mecklenburg County	Totals
Number of families enrolled in Project C.A.R.E.	110	65	44	219
Nonenrolled (consultation, referral, information)	112	126	55	293
.				
Number of Provider Agencies Used (by Type)				
In-home providers	16	18	6	40
Adult day providers	3	2	12	17
Overnight providers	3	4	0	7
Private-pay services	4	0	0	4
Total	**26**	**24**	**18**	**68**
Choice of Respite Type				
Families receiving in-home service	67	28	13	108
Families receiving adult day service	32	25	32	89
Families receiving residential overnight	2	1	0	3
Families receiving private-pay services	3	0	0	3
Families not choosing	6	11	0	17
Total	**110**	**65**	**45**	**220**
Client Gender (Person with Dementia)				
Male	52	18	15	85
Female	58	47	29	134
Total	**110**	**65**	**44**	**219**
Client Race				
African American	9	35	34	78
White	101	29	10	140
Native American	0	1	0	1
Total	**110**	**65**	**44**	**219**
Caregiver Gender				
Male	20	16	6	42
Female	90	49	38	177
Total	**110**	**65**	**44**	**219**