

North Carolina's Support of Family Caregivers

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A significant number of adult North Carolinians are family caregivers. Many try to juggle the demands of children, grandchildren, and jobs, while taking care of their older relatives. By doing this, they often put their own health in jeopardy. According to the 2003 Behavioral Risk Factor Surveillance System Survey, one of every four adults in North Carolina provided regular care for an older adult within the past month.¹ Close to half reported that the person for whom they are caring has memory loss, confusion, or a disorder such as Alzheimer's disease (AD).

Although caregiving is a normative experience for families and plays an integral role in our long-term care system, it does not come without a price. Families providing care to a person with AD usually face a longer and much more difficult journey. As Dr. Taylor asserts in his issue brief,² our society must recognize the staggering quasi-external costs of caregiving (i.e., the deleterious effect on caregivers' immediate and retirement finances, physical and emotional health, family relationships, etc.) and examine the merits of using public dollars to help families care for loved ones at home. Taylor suggested that our inaction in support of caregivers speaks volumes.

The 2001 Report of the North Carolina Institute of Medicine's Task Force on Long-Term Care also called for action:

The Office of Long-Term Care, within the Department of Health and Human Services, should assure that all policy and program development activities consider and respect the importance of family caregiving and examine how to further strengthen the capacity of families to perform their caregiving function.³

While North Carolina has begun to recognize and support the value of family caregivers, we are still in our infancy in developing the array of supports they need.

Because caregivers' needs change as the condition of their loved ones changes, a wide variety of supports must be available through the various stages and circumstances of the caregiving career. More importantly, there must be flexibility in the provision of these supports.

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What Is North Carolina Doing to Support Caregivers?

North Carolina first officially recognized the need to support caregivers of older adults in 1985⁴ when the General Assembly passed respite care legislation and provided some funds to be administered through the (then) state Division of Aging. The statute identified the importance of counseling, support groups, training, access to services, assessment and care planning, and respite for the caregiver through in-home assistance and temporary out-of-home placement. This legislation targeted caregivers of persons age 60 and older, but was later revised to serve also people aged 60 and older who are providing care for an adult of any age. Although these funds helped raise awareness of caregivers' special needs, no concentrated, coordinated effort was implemented on behalf of family caregivers until the creation of the National Family Caregiver Support Program (NFCSP) in 2000.

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Figure 1.
North Carolina's Family Caregiver Support Program

Vision

Families will enter into caregiving with the knowledge and assurance that they can call upon the business, faith, and health and human service communities to assist with information, counseling, problem solving, respite, and formal services when needed.

Care Recipient and Caregiver Characteristics

- The average age of the person receiving care is 80, while more than half (53%) of caregivers are between ages 40 and 59.
- Nearly half of care recipients are cognitively impaired (44%).
- Seven in ten caregivers live with the care recipient.
- More than three-quarters of the caregivers are women (76%).
- Nearly half of the participants are caring for their parents (45%) and about a third (32%) for their spouse.
- Half of caregivers report their own health as 'fair' or 'poor,' as opposed to 'well.'

With the 2000 enactment of the Older Americans Act (OAA) Amendments, the NFCSP became the first federal program with a required focus on the caregiver. The NFCSP, Title III-E of the OAA, is intended to offer a "multifaceted system" of caregiver supports. The NFCSP must contribute to a seamless service delivery system, building on effective services, and developing new services where needed. The legislation allows five broad categories of supports, which correspond closely to those of North Carolina's 1985 Respite Act:

- Information
- Assistance with access to services
- Individual counseling, support groups, and caregiver training
- Respite care
- Supplemental services (on a limited basis) to complement the care provided by eligible caregivers⁵

The primary population served by the NFCSP are the family caregivers of persons aged 60 and older. Family is defined very broadly and includes adults in the immediate family as well as caregivers in the community who provide informal assistance. In many instances, these families are caring for older persons with AD or related dementia. The NFCSP also recognizes and supports grandparents and other relatives age 60 and older who are primary caregivers of minor children. See Figure 1 for further information on North Carolina's Family Caregiver Support Program (FCSP).

The OAA services, including the NFCSP, and state funds to serve community dwelling older adults are administered by the Division of Aging and Adult Services, within the North Carolina Department of Health and Human Services,

through a network of 17 Area Agencies on Aging and hundreds of local providers. The services under its Home and Community Care Block Grant services include home-delivered meals, in-home aide, adult day services, and transportation. These services are available to any person aged 60 and older, although special effort is made to reach seniors who are socially and economically needy. Many of these services provide relief to family caregivers. At the end of 2004, more than 7,500 seniors were on a waiting list for services. In addition, services to at-risk adults of all ages are administered by Division of Aging and Adult

Services through the county departments of social services. One of these services—Adult Protective Services—sheds additional light on the importance and stresses of caregiving. Among the Adult Protective Services-confirmed cases handled in 2003-2004, more than half (54%) involved self-neglect, 26% caregiver neglect, 12% exploitation, and 7% abuse.⁶

Challenges to Implementing a Caregiver Support Program

In implementing the NFCSP, the Division of Aging and Adult Services and the Area Agencies on Aging have had to tackle significant challenges. First, families providing care do not typically identify themselves as being "caregivers." They are just doing what comes naturally as a part of their familial responsibility. Their interest in the use of services is directly related to how their loved one will benefit.

From the program's inception in 2001, North Carolina's version of the NFCSP has emphasized public awareness. Specifically, the program has attempted to reach caregivers and

Figure 2.
How Healthcare Professionals Can Assist Caregivers

Identify and recognize family caregivers.	25% of adult North Carolinians are caregivers of adults 60 and older.
Assess how the caregiver is coping.	Caregiver assessment forms in English or Spanish can be downloaded at http://www.ama-assn.org/ama/upload/mm/36/caregivertooleng.pdf .
Provide information and education on the patient's disease process.	In addition to information that healthcare practitioners provide, caregivers can also refer to the Western and Eastern Alzheimer's Chapters and the Duke Family Support Program.
Encourage caregivers to be a partner in care.	Barring safety concerns, support families' decisions for where care will be provided, whether in an institution or at home.
Refer caregiver for support and further information.	Connect with the Family Caregiver Specialist at the Area Agency on Aging or contact the local Council or Department on Aging.

those who touch their lives, including employers, the faith community, and health and human service professionals. Because caregivers often do not self-identify, public awareness efforts remain critical. Caregivers need to know that they are not alone and that support services are available. Not only is public awareness key to reaching isolated caregivers, it also helps build partnerships and leverage resources.

The healthcare community has a vital role in this outreach and is viewed by the program as an important partner. Figure 2 outlines a view of some of the significant roles that healthcare professionals can assume in the lives of caregivers.

Caregivers often turn to healthcare professionals for information, and not surprisingly, this increases as the caregiver burden grows. Information is cited as the chief unmet need of caregivers in several surveys. The 2004 Caregiving in the United States Survey found that two-thirds of caregivers need more information on a variety of topics.⁷ This figure jumps to three-fourths for those caring for persons with AD. Alzheimer's caregivers report a need for information on resources, help in navigating the system, and managing special behavioral challenges presented by their loved ones.

One successful effort that is helping physicians to better assist caregivers is *Making the Link: Connecting Caregivers with Services through Physicians*. This is a program of the National Association of Area Agencies on Aging and the United States Administration on Aging. Several of North Carolina's Area Agencies on Aging are using the tools of this program to raise awareness within the medical community about how caregiving can present its own health risks and to help physicians connect caregivers to local services when appropriate. In endorsing the program, the American Medical Association asserts, "an effective relationship model acknowledges the key linkage role of the primary care physician and recognizes that caregivers and patients form interdependent units. It also considers the caregiver as a partner with the physician in the care of the patient. The physician demonstrates concern for and carries out periodic assessment of the caregiver as well as the patient and validates the role of the caregiver."⁸

Hopefully soon, physicians and their patients will be better able to access information about community supports throughout North Carolina. A new initiative of the North Carolina Department of Health and Human Services will connect various community resource databases from across the state. This statewide database will be made available on the Internet to aid the location of supports for near-by or long-distance caregivers. Because of the myriad of services provided through a variety of public and private for-profit and not-for-profit agencies, caregivers need easier access to information about these services in making decisions about the care of their family members.

A second barrier to the program's implementation has been the limited federal funding made available, especially relative to need. North Carolina received \$2.9 million in 2001 to start the Family Caregiver Support Program, and this increased to \$3.7 million in 2004. These funds are minimal in comparison to the more than \$868 million spent in North Carolina under Medicaid for nursing home care in 2003.⁹ Without the ongoing support of families, the need and cost of facility care would

surely rise. In introducing the NFCSP to states in early 2001, Edwin Walker, Director of Program Operations and Development at the United States Administration on Aging (AoA), offered these words of advice:

- The Caregiver program offers a chance to change the long-term care paradigm and correspondingly, the long-term care delivery system, to acknowledge the role of informal, unpaid services by caregivers.
- The focus is on the needs of the caregiver as opposed to the care recipient.
- We want to develop and implement multifaceted and coordinated systems of supports, not just services. The focus is on responding to diverse needs of today and building for tomorrow.
- Exercise caution—strategically plan a system of services, assess needs of caregivers, prioritize these needs, find and incorporate research and best practice—integrate, build on and enhance what exists when possible, including use of non-traditional partners as well as the current home and community-based care programs.
- Don't rush to provide services. Avoid the temptation to dump the money into existing respite services just to get it spent.
- AoA is going easy on regulations for the Caregiver program, preferring to allow flexible, innovative implementation at the local level. Don't push AoA to regulate or define things too quickly.
- Build broad-based coalitions that include non-traditional partners and find ways to maximize resources in comparison to need.
- Produce and document desired outcomes—build a foundation to justify the caregiver funding and advocate for additional funds.

Creating Partnerships

North Carolina heeded this advice and saw the need first to address a third challenge to the program's implementation, namely, the absence of a community infrastructure to focus on caregiver needs. The Division responded by creating the position of Family Caregiver Resource Specialist in each of the 17 Area Agencies on Aging located within regional Councils of Government across the state. These Resource Specialists are charged with building the multifaceted and well-coordinated system of supports that caregivers need. With limited public funds available, the specialists work to create partners and leverage resources whenever possible. Their success in this regard, along with the increasing number of local specialists, is largely responsible for the program's effectiveness to-date. With input from many different community agencies and groups and from caregivers themselves, these specialists have seeded numerous new and unique partnerships.

Strong partnerships with statewide organizations [i.e., North Carolina Cooperative Extension, Duke Family Support Program, AARP-NC, and The Carolinas Center for Hospice

and End-of-Life Care] have provided significant support in the development and implementation of the Family Caregiver Support Program. For example, the North Carolina Cooperative Extension Aging Specialist and a social worker from the Duke Family Support Program became master trainers for a highly acclaimed caregiver curriculum the "Taking Care of You: Powerful Tools for Caregivers." With the assistance and financial support of AARP-NC, class leader workshops for this and other caregiving curricula were held across the state. Locally the Area Agencies on Aging, Cooperative Extension, AARP Health Specialists, and others now partner to deliver these workshops directly to caregivers across the state.

AARP-NC has further demonstrated its strong commitment to caregiving with two publications: the *Family Caregiving in North Carolina* guidebook and a *Grandparents Raising Grandchildren Guide*. These publications were developed with input from many participating partners. AARP-NC has also sponsored surveys and conferences aimed at helping businesses support caregivers in the workplace.

North Carolina is fortunate to have very strong professional and consumer resources focused specifically on AD. These resources have been instrumental to the implementation of the FCSP.

Since 1994, the General Assembly has invested in services for families affected by AD by helping fund programs of the Eastern North Carolina and Western North Carolina Chapters of the Alzheimer's Association. Their programs include support groups, caregiver workshops, maintaining a library of educational materials, toll-free help-lines, and many other services. Caregivers are learning first-hand about AD and strategies for managing challenging behaviors, and their association with others in similar situations helps reduce feelings of isolation. A calendar of events for the Eastern Chapter is found at <http://www.alznc.org> and for the Western Chapter at <http://www.alz-nc.org>. Since 2001, each of the

two Chapters has received \$75,000 in state funds, which has been critical to their operation.

Duke's Family Support Program, with an emphasis on dementia-specific supports, also receives state funds. Since 1984, the program has used its \$50,000 to serve as a one-stop clearinghouse, crisis hotline, and technical assistance center for families and professionals caring for people with memory disorders. The state funding of the Alzheimer's Chapters and the Duke Family Support Program also has enabled North Carolina to leverage other resources. For example, it is helping provide the required matching funds for the federal Alzheimer's Demonstration Grant that the Division of Aging and Adult Services is currently administering and that is described in the commentary by Karisa Durence.¹⁰

The fact that North Carolina has chosen to support Alzheimer's-specific services is admirable among states. The fact that these funds have been stagnant is cause for reflection and concern. The number of family caregivers, including those of persons with AD, is growing dramatically with the aging of our state's population.

How Is the State Addressing Policy Issues?

Our nation, state, and local communities face a monumental challenge in meeting the long-term care needs of the aging population. As the state continues to move forward to meet the requirements of the United States Supreme Court's Olmstead decision for promoting the least restrictive care environment, family caregiving will inevitably play an even more critical role.

The North Carolina Department of Health and Human Services is the recipient of several grants through President Bush's *New Freedom Initiative*. These "systems change" grants through the Center for Medicare and Medicaid Services are charged with improving the infrastructure, availability, and

North Carolina Department of Health and Human Services: Resources for Caregivers by Division

<http://www.dhhs.state.nc.us/docs/division.htm>

Division of Aging and Adult Services

Information and assistance, adult day services, in-home aide services, respite, caregiver support, transportation, home delivered meals, adult protective services, elder rights, long-term care ombudsman, guardianship, case and care management, adult placement services, Special Assistance In-Home Program (in selected counties),

Division of Services for the Blind

Adjustment to vision loss, counseling, information and instruction in basic living skills.

Division of Services for the Deaf and Hard of Hearing

Regional Resource Centers

Division of Medical Assistance

A Medicaid waiver program: Community Alternatives Program for Disabled Adults (CAP/DA)

Division of Mental Health, Developmental Disabilities and Substance Abuse Services

Area Programs

Division of Vocational Rehabilitation

North Carolina Assistive Technology Program

quality of community services available to adults with disabilities. As envisioned, informed consumers will increasingly have the opportunity to direct their own plan and delivery of service supports. While these grants enhance work on systems change, demand for community services continues to exceed availability.

As society hears increasingly about the value of quality care in the setting of choice, government struggles with how to pay for this care for many of its citizens whose resources are inadequate or quickly diminish with the high cost of care. Government must operate under a responsive long-term care system where the caregiving contributions of families are valued and supported. Just as businesses are realizing the economic sense of responding to the interests and needs of working caregivers, support of caregivers is sound public policy.

This year (2005) the NFCSP comes up for reauthorization under the Older Americans Act. Also this year, the fifth White House Conference on Aging is scheduled, October 23-26, 2005. The previous conferences, held in 1961, 1971, 1981, and 1995, were significant in their policy recommendations to the President and Congress. They also assisted the public and private sectors in identifying emerging trends and preparing for

current and future generations of older persons. One of many important issue areas will surely be health and long-term care and within this discussion, the importance of investing in family caregiving.

North Carolina's delegates to the White House Conference will be able to voice their opinions on the NFCSP and other public policy considerations, such as the proposed Ronald Reagan Alzheimer's Breakthrough Act of 2004. This bill would double funding for AD research at the National Institutes of Health (from \$700 million to \$1.4 billion); support a National Summit on Alzheimer's Disease; and increase the availability of services, such as respite care, home healthcare, counseling, and training. The bill also proposes to double funds for the NFCSP (from \$125 million to \$250 million) and the Alzheimer's Demonstration Grant Program (from \$12 million to \$25 million).

Both nationally and in North Carolina, we must follow the lead of the Task Force on Long-Term Care of the North Carolina Institute of Medicine, in finding "ways to invest in family caregiving so that it can be sustained as a primary resource for long-term care, reducing the risk for needing formal, publicly-financed services." **NCMJ**

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