

There's No Place Like Home

T. Lee Covington

People typically wish to remain in their homes as they age. Although many community-based services exist to support this wish, people often are unaware of these resources and seek institutional placement instead, thinking that it is their only option. This commentary aims to address this lack of information by discussing various stay-at-home options.

Dorothy in *The Wizard of Oz* said it best: "There's no place like home!" However, as people age and slowly become more dependent on others, they may question the idea of remaining in the home where they have lived for many years. Many believe that they have few options for securing the necessary support and services they need to gracefully and safely age in place. As a result, individuals and families often default to institutional settings such as nursing homes or assisted living facilities. Although such facilities are a necessary part of the array of services available for senior citizens and people with disabilities, these facilities may not be the best choice for everyone. In North Carolina, there are many community-based options and organizations that provide a full array of services designed to support individuals who wish to remain in their homes. The rapid growth of the older adult population is increasing the demand for these services.

Home and Community Care Block Grant Programs

In 1965 Congress passed the Older Americans Act (OAA) [1] as a response to a grave lack of community social services for senior citizens. The law established the Administration on Aging to administer grant programs and to serve as the federal focal point on issues concerning older adults. Today the OAA is the major pipeline for the delivery of social and nutrition services to older adults and their caregivers. An array of services is provided by a national network of 56 state agencies on aging, 629 area agencies on aging, nearly 20,000 service providers, 244 tribal organizations, and 2 Native Hawaiian organizations representing 400 tribes.

Federal dollars originating with the OAA are distributed to each state based on a funding formula. North Carolina rolls these funds into the Home and Community Care Block Grant (HCCBG), which is supported by approximately 34% federal OAA funds, 3% Social Service Block Grant funds, and 52% state funding. A local match (cash or in-kind) of at least 10% is required to secure HCCBG funding. Recent figures show that local matching was 11.5% (written commu-

nication from Heather Burkhardt, North Carolina Division of Aging and Adult Services; August 13, 2014). The North Carolina Division of Aging and Adult Services allocates HCCBG funds to all 100 counties in North Carolina based on a weighted funding formula. All 100 counties are a part of the Aging Network and work with Area Agencies on Aging for administrative support, quality assurance, and technical assistance. The Aging Network is a strong, well-structured network that has been in place for over 40 years. This network is made up of 1 state unit on aging, 16 Area Agencies on Aging, and more than 400 funded partners across North Carolina. More information on these agencies is available from the North Carolina Association of Area Agencies on Aging (www.nc4a.org).

There are 18 services available under the HCCBG program, although not all services are available in all areas of the state. These services include congregate nutrition, home-delivered meals (Meals on Wheels), adult day care, adult day health care, care management, skilled home (health) care, housing and home improvement, information and case assistance/options counseling, in-home aides (levels I-IV), senior companions, transportation, group respite, health promotion and disease prevention, health screening, institutional respite care, mental health counseling, senior center operations, and volunteer program development.

Meals on Wheels is perhaps the best known and most broadly available of these services. (A current list of meal providers can be accessed at <http://www.ncdhhs.gov/aging/services/hdm.htm>.) Many such programs use volunteers to deliver hot meals up to 5 days a week, making the program much more than just a meal. A recent study by Brown University public health researchers estimated that if all of the lower 48 states in the United States were to expand the number of senior citizens receiving meals by just 1%, then 1,722 more Medicaid recipients could avoid living in a nursing home, and most states would experience a net annual savings from the expansion [2].

Adult day service programs may be one of the best-kept secrets in the array of services included in the HCCBG program. A study by a research team at Penn State University [3]

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A North Carolina Service for Those With Questions About Alzheimer Disease, Other Memory Disorders, and Family Care

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The Duke Family Support Program (DFSP) is a service for North Carolina families and professionals who are caring for someone with a memory disorder. The program offers telephone and e-mail consultations, clearinghouse services, and education to North Carolina professionals, family members, and friends caring for any adult with declines in memory. The DFSP has been answering questions about dementia since 1979—long before there were daily headlines about brain health and celebrity testimonials about the effects of Alzheimer disease on families.

Duke's original Alzheimer disease evening support group has been meeting monthly since 1979. The program was started to address the needs of a group of families of people with early-onset Alzheimer disease, many of whom were participating in the first federally funded study of Alzheimer disease at Duke University. These family members were frightened, exhausted, and alone, and they were eager to learn from others facing similar challenges and to hear from credible and interested professionals. This open, community-based group offers practical consumer information, coping tips, and opportunities for families to connect and learn that they are not alone.

DFSP social workers also facilitate 3 other groups for individuals with memory disorders and their families. With leadership from DFSP social workers, the Bryan Alzheim-

er's Disease Research Center sponsors the Cary and Ruth Henderson Person with Dementia and Care Partner Support Group, which is named to honor the original participants. This couples group has been meeting monthly since 1992. A second group is the Daughters Concerned for Aging Relatives. This monthly support group has been meeting since 1996 and draws Triangle-area adult daughters, daughter-in-laws, and granddaughters, who share problem-solving approaches as well as laughter, tears, chocolate, and knowledge. Finally, the Early-Stage Alzheimer's Education and Support Group is the DFSP's newest initiative, now going into its third year. Serving individuals with a recent dementia diagnosis and their care partners, this evidence-based program is a partnership between Duke University, Jewish Family Services, and the Alzheimer's Association. This program has so far offered educational, emotional, and social support—3 hours a week for 8 weeks—for 5 groups of up to 13 couples; support is provided through a mix of lectures, full-group discussions, and separate group discussions for diagnosed individuals and for their care partners.

The Early-Stage Alzheimer's Education and Support Group serves as a portal to a thriving community of group "graduates." These individuals meet monthly with a DFSP social worker for lunch at a local restaurant, and they par-

found that people with Alzheimer disease and other types of dementia showed improvements in behavior, mood, and sleep when they participated in an adult day service program, and their family caregivers experienced decreased daily stress. According to this study, the activities and social interaction provided by adult day service programs are an effective nonpharmacological way of treating people with dementia:

Adult Day Service programs engage people in stimulating and therapeutic activities during the day. The positive benefits of these activities carry over when clients go home. They are more relaxed and sleep better after a day of meaningful activity.

According to the Penn State study, the improvement in behavior and mood achieved by adult day service program is similar to, or greater than, the improvement provided by available medications for persons with dementia, without the adverse effects [3].

This study also found that being able to send a spouse or parent to an adult day service program reduced family caregivers' daily stress levels by about 40% [3]. "Adult day services create a win-win situation for everyone involved," said

Elia Femia, a codirector of the research and coauthor of the article. "The person with dementia benefits by participating in engaging activities, while the family caregiver gets a helpful break" [3]. Family caregivers sometimes report that it is difficult to get their relative ready in the morning to go to an adult day service program. However, this study found that morning routines were not, on average, more challenging for caregivers on mornings when their relative went to an adult day service program [3]. A complete list of currently licensed adult day service programs in North Carolina is available on the North Carolina Division of Aging and Adult Services Web site [4].

Waiting lists. Although the list of services available through the HCCBG program is impressive, flat or decreasing funding has led to growing waiting lists for these services. In addition, due to the increasing cost of providing services, flat funding actually equates to a decrease in the volume of services available. According to a survey of HCCBG providers conducted in April 2013 [5], about 16,000 senior citizens were on the waiting lists for HCCBG services, 66% of whom were waiting for an in-home aide or home-delivered meals. The third-longest waiting list was for housing/home repair, followed by adult day services, transportation, and congre-

ticipate in a “look and lunch” arts program at Duke’s Nasher Museum of Art. All programs are facilitated by individuals with a master’s degree in social work and are free and open to the public.

In addition to programs, the DFSP publishes a newsletter, *The Caregiver*, which has its roots in the original support group’s desire to share stories and tips. Now published twice annually and circulated free of charge to 11,000 readers, *The Caregiver* is the oldest continuously published family caregiver newsletter in the United States.

The DFSP also offers the following services and information to all North Carolina residents at no cost: help with care decisions and coping strategies; personalized tips on caring for people with memory disorders; research updates and options for participating in studies of Alzheimer disease treatments, caregiving, and prevention; help in choosing support groups, education programs, online resources, or books; and a comprehensive, regularly updated information packet on Alzheimer disease.

Finally, the DFSP serves North Carolina agencies, employees, and community groups by providing technical assistance and training programs for agencies who serve individuals with Alzheimer disease or their caregivers; outreach to and education of community groups through presentations, “lunch and learn” programs, and information tables; and Project C.A.R.E. (Caregiver Alternatives to Running on Empty), which offers individualized consultations for families in central North Carolina. The DFSP also operates the Duke Employee Elder Care Consultation Service, which provides work site family consultations, often

during crises, for Duke employees who are facing eldercare decisions.

Since 1984 the DFSP has been partially funded by the Division of Aging and Adult Services of the North Carolina Department of Health and Human Services; the remainder of the program’s funding comes from research grants and contracts. The program continues to serve as a state barometer of family needs and preferences and of gaps in health and social support services. NCMJ

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gate nutrition. More than half of providers said that county funds were being reduced or eliminated, and more than one-third of providers said that they had fewer volunteers and that those volunteers were working fewer hours. Of providers that offer information and assistance, 71% reported increased requests for their help, but 46% said they had fewer community resources to which they could refer people. Additionally, 81% of senior centers in the state reported increased demand and attendance [5]. These statistics are the result of dramatically increasing demand during a period of flat or decreasing funding.

Private-payment services. Many providers across North Carolina have waiting lists for most or all of their services that are funded through the HCCBG program. As a result, many are branching out into a new business model and are offering services on a private-payment basis—meaning they charge a fee for services, and this fee is paid by the recipient and/or his or her family. Private-payment rates vary by location and provider. Aging, Disability and Transit Services of Rockingham County has taken this concept a step further through the creation and implementation of their new @Home Assisted Living program. @Home Assisted Living bundles 4 core services—in-home aide, Meals on Wheels,

transportation, and adult day care—into various packages designed to meet a wide variety of needs. Seniors can also design their own packages with any of the aforementioned services at whatever level meets their unique needs. Many long-term care insurance policies cover some of these services. To access these private-payment services, families can contact their local senior services agency or visit www.nc4a.org for a complete list of Area Agencies on Aging.

Volunteer services. Many local communities have been able to meet their needs by using teams of dedicated volunteers, although not all communities have volunteer programs. Churches, synagogues, and other community groups can make a real difference by organizing volunteers to extend the reach of HCCBG services. Information about volunteering can be obtained from a local senior services agency or the local Area Agency on Aging. A complete listing of Area Agencies on Aging can be found at <http://www.ncdhhs.gov/aging/aaa.htm>.

The Community Alternatives Program for Disabled Adults

The Community Alternatives Program for Disabled Adults (CAP/DA) is a Medicaid Home and Community-

Program of All-Inclusive Care for the Elderly: A Comprehensive, Cost-Effective Alternative for Frail Elderly Individuals

Linda Shaw

The Program of All-Inclusive Care for the Elderly (PACE) is a capitated health care program that allows individuals who qualify for the level of care provided by a nursing home to remain in their communities instead. PACE meets a critical need in the continuum of care for frail elderly individuals, providing a high-quality, cost-effective, community-based alternative to institutionalization. This innovative program includes comprehensive care provided by an interdisciplinary team, a medical day program, patient care coordination, intensive work with families, and provision of transportation and home care as needed. As part of this program, PACE provides and pays for all medically necessary services, including primary care, hospital care, specialty care, and institutional long-term care; it is thus both a health care provider and an insurer.

Each PACE program is a 3-way partnership between the Centers for Medicare & Medicaid Services (CMS), the Division of Medical Assistance in the North Carolina Department of Health and Human Services, and the health care organization operating the program. PACE was authorized as a permanent Medicare provider in 1997 and was approved as an optional Medicaid service in North Carolina in 2007. To enroll in PACE, an individual must qualify for the level of care provided by a skilled nursing facility, be 55 years of age or older, reside in an area served by PACE, and be able to live in the community with support. On average, PACE participants are 80 years old, have 8 medical conditions, and are taking up to 12 medications when they

enroll. Almost half (48%) have a dementia diagnosis [1]. In addition, most participants have low incomes; approximately 96% of North Carolina participants are eligible for Medicaid.

PACE assumes *full* risk for participants' medical care and expenses in exchange for a capitated payment that covers every aspect of the participant's care. All health care for the participant is coordinated through, paid for, and/or delivered by PACE. Because PACE is responsible for all costs, PACE providers have a great incentive to keep participants as healthy as possible, to practice preventive measures, and to take a holistic and pre-emptive approach that will keep participants out of hospitals, emergency departments, and nursing homes.

The PACE model integrates medical care with social, family, environmental, and other factors that influence the participant's health. An interdisciplinary team consisting of physicians, nurses, social workers, therapists, and other professionals evaluates each participant and works collaboratively to determine and implement a unique, comprehensive plan of services. Transportation, meals, exercise, therapy, socialization, personal care, medication, and medical attention are provided at the PACE health center and at the participant's home, as needed. Because caregiver fatigue is a key factor in institutional placements, PACE also provides support, information, and respite for family caregivers.

This model has produced excellent health outcomes.

Based Services Waiver authorized under section 1915(c) of the Social Security Act. (A description of these services can be found in section 440.180 of Title 42 of the Code of Federal Regulations [6]. Federal regulations governing such waivers are in Part 441 Subpart G of Title 42 of the Code of Federal Regulations [7].) The CAP/DA program waives certain North Carolina Medicaid requirements and furnishes an array of home- and community-based services to adults with disabilities who are 18 years of age or older and are at risk of institutionalization. The services are designed to provide an alternative to institutionalization for beneficiaries in this target population who prefer to remain in their primary private residences. Services provided through the CAP/DA waiver program include adult day health; personal care aide; home accessibility and adaptation; meal preparation and delivery; institutional respite services; noninstitutional respite services; personal emergency response services; specialized medical equipment and supplies; participant goods and services; community transition services; training, education, and consultative services; assistive technology; case

management; care advisor (available only to patients in the Community Alternative Program for Choice [CAP/Choice]); personal assistant (CAP/Choice only); and financial management services (CAP/Choice only) [8].

The Home and Community-Based Services Waiver allows the state to offer home- and community-based services to individuals who meet the following criteria: they require a level of institutional care under the North Carolina State Medicaid Plan; they belong to a target group included in the waiver; they meet applicable Medicaid eligibility criteria; they require more than 1 waiver service, including case management, in order to function in the community; and they are voluntarily choosing to enter the waiver in lieu of receiving institutional care. Eligibility for the CAP/DA waiver is limited to Medicaid beneficiaries who are adults with disabilities (18 years of age or older) who are in the aged, blind, or disabled Medicaid eligibility categories [9].

As with HCCBG services, there are currently waiting lists for CAP/DA services. In Rockingham County, the waiting list averages around 140 people, and individuals can wait

According to the executive director of Piedmont Health Senior Care, during the period from January 1, 2010 to December 31, 2013, participants in this North Carolina PACE program experienced 0.4 hospitalizations per member per year, 0.3 emergency department visits per member per year, and a low rate of hospital readmissions; all of these rates were lower than those of comparable participants in other Medicaid programs. Despite being eligible for nursing home care, only 6% of PACE participants were in a nursing home or assisted living facility, and more than one-third (35%) were living at home alone, with PACE support. The remainder of participants (59%) lived with a caregiver in the home. Nationally, only 8% of PACE participants reside in a nursing home, and the average length of time in the program is 3 years [1].

PACE also saves money for the state Medicaid program. As both the insurer and the provider, PACE assumes full financial risk for its participants; there is no cost to the state beyond the capitated payment. If a participant ultimately requires nursing home care, PACE pays for it. Specialist care, tests, dental care, vision care, and end-of-life care are all provided either directly by the PACE organization's staff members or through its network of contracted providers. The all-inclusive PACE capitated payment from Medicaid is less than the cost of a nursing home, yielding savings of at least \$16,800 annually for every Medicaid-eligible person PACE keeps in the community. In addition, the state can forecast and control Medicaid expenditures for the rapidly growing population of individuals over age 65 years; these costs were otherwise predicted by CMS to grow more than 8% per year through 2020 [2].

North Carolina's first PACE program, Elderhaus, opened in Wilmington in 2008. Nine PACE programs now operate

at 10 sites in Wilmington, Burlington, Fayetteville, Greensboro, Lexington, Newton, Charlotte, Durham, Pittsboro, and Gastonia. All operating organizations are not-for-profit entities in the predominantly low-income communities they serve. PACE programs in Asheville and Asheboro should open by 2015, and additional communities also have been targeted for programs pending state approval.

In June 2014, slightly more than 1,000 North Carolinians were enrolled in PACE. These programs have grown steadily in North Carolina, but Medicaid funding and administrative issues have curtailed growth substantially. NCMJ

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9-12 months to receive services. As an interim measure, many people apply to receive limited services through the Personal Care Services (PCS) program.

PCS Program

The PCS program, which took effect on January 1, 2013, is a Medicaid State Plan benefit designed to provide personal care services to individuals who reside in one of the following settings: a private living arrangement, a residential facility licensed by the state as an adult care home, a combination home (a nursing home offering any combination of skilled nursing, intermediate care, and adult care home services [10]), or a group home licensed by the state as a supervised living facility for 2 or more adults whose primary diagnosis is mental illness, developmental disability, or substance abuse dependency [11].

PCS services are available to individuals who have a medical condition, disability, or cognitive impairment and who meet one of the following criteria: they need limited hands-on assistance with 3 of the 5 qualifying activities of daily living

(ADLs); they need extensive assistance with at least 1 ADL and some type of assistance with 1 other ADL; or they need assistance at the full dependence level with at least 1 ADL and some type of assistance with 1 other ADL. The 5 qualifying ADLs are eating, dressing, bathing, toileting, and mobility. PCS program eligibility is determined by an independent assessment conducted by the North Carolina Division of Medical Assistance or its designee, and services are provided in accordance with an individualized plan of care [11].

Essential Services for Safe Transitions

With an increasing national focus on successfully transitioning patients from hospitals to their homes, community-based services are now more important than ever. Unfortunately, much of the medical community seems to lack awareness and recognition of the value of these services. There are several ongoing demonstration projects in North Carolina looking at ways of encouraging a smooth transition from health care facilities to homes, as well as supporting people so that they can remain at home once

they have made this transition.

Services such as those mentioned previously are often essential to ensuring a successful transition. Rockingham County conducted a 15-month pilot project in 2012 and 2013 and found that people were often rehospitalized because of social isolation, hunger, or an inability to understand medication changes. The services discussed in this article are an integral part of the solution, but there is a need for additional funding from all levels—local, state, and federal. The recently approved state budget included a 3% cut to HCCBG funds (\$969,549). *NCMJ*

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