Long-term Care for the Elderly: What Promise for the Future?

by Robert Conn

The continuum of health services for older persons has widened in recent years to include everything from hospital and nursing home care to home health services and adult day care. Reimbursement for long-term care—usually Medicare or Medicaid—often determines the location of care on this continuum. "Who will pay?" has become the overriding question rather than the more appropriate question: "What kind of health care does the person need?" What can policymakers do to help the long-term care delivery system emphasize the appropriate level of care for an older person?



he Biblical promise of a life of three score years and ten is being fulfilled for millions of Americans, and even a life of five score years no longer ensures a news article. The longer lives are the results of unprecedented medical progress—the eradication or control of most infectious diseases, plummeting heart disease deaths, and millions surviving cancer.

Increasingly accurate diagnostic devices enable treatment of once bizarre diseases. and sophisticated therapeutic equipment produces cures once thought impossible. Invention of life support equipment has changed the very definition of death.

It's an era when the thump-thump of the respirator is heard in the bedroom as well as the hospital room, when the once-feared correction of cataracts has become drive-in surgery, when diseased arteries are routinely bypassed to add decades to life.

But the added years are a mixed blessing, as people push the upper limit of the human lifespan. Longer lives have unleashed lingering, often incapacitating illnesses problems scarcely identified just a few years ago. 1 Names like Alzheimer's disease have gone from medical specialty texts to newspaper headlines. Many attribute the increas-

John and Lois Horn at home, not in a hospital

ing cancer rates to an aging population, where odds a cell will go awry increase dramatically.2

The cost of treating the elderly has soared so rapidly that some experts fear Medicare will be bankrupt by the end of the decade. The numbers are awesome. Already, people 65 and over represent 11 percent of the population. Those over 85—the "very" old-now total 2.2 million people, about 1 percent. In North Carolina, the number of elderly people will climb from about 600,000 in 1980 to nearly one million by the turn of the century. Those over 85 will increase from 45,000 to 103,000 by the year 2000 (see demographics article on page 3).

Though almost everyone knows someone over 85 who is alert, fit, and spry, others are so infirm they are hardly alive. Many need help with personal care—such basic activities as bathing, dressing, going to the toilet, and even eating.

Robert Conn, a reporter for The Charlotte Observer and The Charlotte News, has covered health-related stories for two decades.

"Over 90 percent of nursing home patients are dependent on personal care," says William G. Weissert, director of the program on aging at the University of North Carolina School of Public Health in Chapel Hill, and consultant to many experimental projects in caring for the elderly in the state.

Many families try to care for an infirm person at home, like the family of John Horn of Charlotte. Interviewed in December 1984, Horn was avidly watching a tennis match on color television in his bedroom. Beside his bed, a respirator thumped steadily. Every few seconds, the machine sent life-sustaining air through a tube attached to a hole in the 73-

"We all want to live a long time, but no one wants to get old."

—Author
Unknown

year-old man's throat. The air pumped into Horn's emphysema-damaged lungs. Arrayed around the bed were other pieces of sophisticated equipment, such as a suction machine.

Suddenly the respirator sounded an alarm. Too much fluid was in the lungs for John to continue breathing. In rushed his wife, Lois, 67, who has been trained to suction the excess fluid and otherwise care for her husband. A few minutes later, Horn was breathing normally again.

Just a few years ago, such a scene at home would have been unthinkable. Horn likely would have had to stay in the intensive care unit at Charlotte's Presbyterian Hospital indefinitely—and he already had been there 2½ months. (He was considered too sick for a nursing home to accept.) Now it's possible for John to be treated at home.

Though a nurse checks in on Horn weekly, essentially Lois Horn and two daughters share taking care of John. They consider themselves on duty around the clock. When he first got home from the hospital—he was sent directly home from intensive care—family members often were roused in the middle of the night by the sounding alarm.

Though the Horns share the burden, in many families there's only one care-giver. Constant provision of personal care often leads to care-giver burnout and to permanent placement of the parent in a nursing home. As concern grows about the cost of institutional care, many experts are beginning to focus on the care-giver. If the care-giver can get routine relief and assistance, perhaps nursing home admissions could be reduced.

If the Medicare system has severe financial troubles and if care in the home burns out the care-giver, what kind of long-term care system is evolving? Do sick or infirm older persons have to make an either-or choice: go into a nursing home or become a burden on children? Put another way, do reimbursement systems—Medicare, Medicaid, other government assistance programs, and limited private insurance—force an older person into an institution when some kind of community care or home care might be sufficient?

These reimbursement systems, plus an individual's personal resources, pay for health care through what has come to be called the long-term care continuum. The spectrum of settings for health care for elders ranges from hospital to home. It includes nursing homes, home health care, rest homes, and in-home services (such as chore workers), as well as newer innovations such as adult day care, hospice, and respite care. At any one time, the vast majority of the elderly are not sick at all, and therefore are not part of the long-term health care system. Furthermore, many elderly people die quickly, in their own homes, after leading independent and productive lives until virtually the last moment.

A broad view of long-term care includes services for people who can't be classified as sick, but who no longer are truly independent. They include rest homes, life-care facilities, meals on wheels, and various social services. Long-term care means "services to people who are not fully able to care for themselves," says a state pamphlet. "The main idea is to provide what help people need to get them through the day."

Federal and state lawmakers, faced with spiraling health care costs, want to know the least expensive long-term-care option. Meanwhile, UNC's Weissert and others warn against making cost effectiveness the key question in considering home and community-based care. Most people who use home and community-based care would not normally go into a nursing home, says Weissert. "We know this now from nearly a dozen stud-

ies in which control group experiences show that 75 to 98 percent of home and community care users would have avoided a nursing home admission whether they received home care or not," writes Weissert.4

Expanded home-health care and expanded institutional care will be needed in future years, as the graying of the population accelerates. If government reimbursement systems are strained now, what will happen as the demand for long-term care increases? Will individuals be forced to pay for a growing share of care themselves, or go withoutthe situation that often prevailed before Medicare and Medicaid began in the mid-1960s?

The Long-term Care Continuum— Who Pays?

railed as health care salvation for the **11** elderly during the "Great Society" of the Johnson Administration, Medicare has fallen short. It is supposed to function as a federal health insurance program to "cover" some 27 million older people. But Medicare in fact is paying a steadily declining percentage of their health care costs.

When all medical bills are taken into account, the portion paid by Medicare is about 39 percent. "That can leave a very large amount for you to pay out of your own pocket if you have no other health insurance. if your income isn't low enough, or if your assets are too substantial to qualify for Medicaid public assistance," reports the American Association of Retired Persons (AARP), the largest advocacy organization for older persons in the country, in a recent publication on Medicare.5

"This decline (in Medicare payments) means that Medicaid and the state will have to absorb more of the costs, or that the elderly will have to pay more," Ernest Messer, former director of the N.C. Division of Aging, told a 1984 national citizens board of inquiry hearing in Charlotte on problems of aging. "If they can't pay more, they will have to forgo some medical care."

Medicare has two parts. Anyone 65 or over qualifies for Medicare Part A (with a few exceptions such as non-citizens, some government employees, and some prisoners). This is basically a *hospital* insurance system, with limited coverage for skilled nursing homes and home health services. Part B. a voluntary insurance system, covers physician services, hospital outpatient services, and

other medical services and equipment. Persons 65 or over can purchase Part B for \$15.50 a month. In FY 84 in North Carolina, Medicare Part A reimbursements totaled \$871 million. Under Medicare Part B, reimbursements were \$260 million; North Carolinians paid Part B premiums of \$126 million. The Health Care Financing Administration (HCFA), the federal agency that administers Medicare, found that in 1982 Medicare paid about 70 percent of its benefits for hospital care, 22 percent for physicians' services, 5 percent for nursing home care, and 3 percent for other costs.

Despite promising coverage of nursing home costs, Medicare now pays less than 5 percent of the total bill for nursing home care. And, sadly, the fine print on most private Medicare supplemental policies—socalled medigap coverage—carefully tracks Medicare coverage. So what is not covered by Medicare often is not covered by the supplemental policies either.

Take doctor coverage. Medicare Part B pays 80 percent of what it deems to be "reasonable" physician charges. The patient or a private policy must make the 20 percent copayment. But because "reasonable" is not a precise term, Medicare averages paying closer to 50 percent instead of 80 percent. reports the AARP, leaving the beneficiary responsible for a payment of 50 percent of Part B charges.

> "Will you still need me, will you still feed me, when I'm 64?" —John Lennon Paul McCartney

"The required 20 percent co-payment and the all-too-frequent difference between what Medicare allows as 'reasonable' charges and actual doctors' fees can add up to a sizable amount of medical costs," notes the AARP. Moreover, medigap insurance usually pays only the 20 percent co-payment, not the difference between the "reasonable" charge and the actual doctor's charge.6

In addition to doctor coverage, Medicare administrators are tightening other reimbursement rules. "The nature of what is considered skilled nursing care is under fire," reports Judy Adams of the N.C. Association for Home Care. Medicare administrators are denying coverage of home care for some of the most severe post-surgery wounds—those that require drainage or are so deep that the bone is exposed-says Adams, who is a nurse. "That is the kind of wound that no nurse would say does not require the skills of a nurse."

When Medicare administrators determine someone has recovered to a reasonable point termed "maintenance," Medicare now routinely cuts off further home treatments, continues Adams. Medicare might cut off further payment, for example, when a stroke victim has progressed from a wheelchair to a walker even though the person could learn to use a cane, which might make the person virtually independent again.

The main reason for such actions is cost. Nationwide, Medicare has soared from a \$4.5 billion program in 1967 to a \$66 billion program in 1984. In 1983, the Reagan administration and Congress addressed the rising costs by instituting a new prospective payment system for Medicare. Under this system, a hospital must classify a patient by type of disease, known as diagnosis related groups, or DRGs, prior to treatment. Hence,

the hospital knows what it will be reimbursed for that treatment before providing the care. Formerly, a hospital treated a person and then billed Medicare for those services.

Leading spokespersons from the health care industry credit DRGs with holding down costs. "Reports about the impending bankruptcy of the Medicare Hospital Insurance Trust Fund ... have proven premature," says Samuel H. Howard, vice president and treasurer of the Hospital Corporation of America, the nation's largest hospital chain. The fund, once expected to run out of money in 1991, now is expected to be solvent for seven more years, until 1998. The new prospective payment system "has given hospitals for the first time incentives to reduce costs," says Howard. "Hospitals are being forced to manage better their facilities, admissions, and the care of all patients."7

But others say the new DRG system pushes people out of hospitals before they are ready, into other parts of the long-term care system. For instance, U.S. Sen. John Heinz (R-Pa.), chairman of the Senate Special Committee on Aging, charges that under DRGs, patients are being discharged "quicker and sicker, and some may even be discharged

A Very Special Nurse: Kay Falls of Presbyterian HomeCare visits one of her home patients, the Rev. William Baxter at Presbyterian Hospital.



prematurely." Many are "being sent out into a no-care zone, without access to the health care they so urgently need," adds Heinz. Consequently, some people who still need care in a hospital are going to nursing homes, rest homes, or returning home. As the location of care shifts, so does the payment system for that care.

By far the largest reimbursement system for health care for older persons, outside of Medicare, is Medicaid. In FY 84, total Medicaid expenditures (federal, state, and local) in North Carolina were \$648 million; \$242 million, or 37 percent, went to people 65 and over. This was almost as much as Medicare Part B in North Carolina (\$260 million), and far more if you subtract the \$126 million in premiums paid for Part B. Of that \$242 million, \$199 million went for institutional care.

In North Carolina, 66 percent of the persons in skilled nursing facilities receive Medicaid assistance. About 79 percent of the patients in intermediate care facilities receive Medicaid.8 (Skilled nursing homes—for licensing, certification, and funding purposes -must have more intense levels of care than intermediate care facilities.)

These figures and percentages illustrate what many lawmakers and health-care administrators already know: While designed as a health insurance program for **poor** people, it has become, in large part, a health insurance program for older persons. Much of the Medicaid funds must come from state and local taxes, so state legislators and county commissioners pay close attention to Medicaid costs. Nursing home populations affect overall state and county budgets-roads, schools, parks, the works.

Federal funds pay about 67 percent of the state's Medicaid expenses; state and local funds pay the other 33 percent.9 Federal and state laws determine who can qualify for Medicaid and what services are to be covered. Consequently, eligibility and reimbursable services under Medicaid vary from state to state. In North Carolina, persons may qualify for Medicaid by being classified as either "categorically" or "medically" needy. Because you have to receive public assistance to qualify as "categorically" needy, most older persons qualify for Medicaid as "medically" needy.

But the medically needy category often sets up a kind of Catch 22 situation. For example, Medicaid will pay for home health services such as physical therapy and nursing care. But Medicaid eligibility guidelines put a "cap" on a person's living expenses so that, ironically, few can afford to stay at home and hence take advantage of Medicaid's home-health care coverage. Many believe Medicaid's cap on living expenses virtually forces a person who must get assistance from Medicaid into a nursing home.

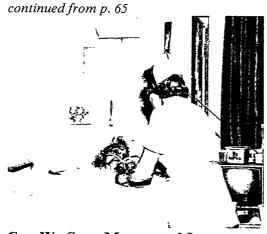
Typically, that cap limits the Medicaid recipient to \$200 a month in living expenses. Any income above \$200 must be spent for medical expenses before Medicaid kicks ina process known as the Medicaid "spend down." All household expenses—food, clothing, utilities, rent, transportation, etc.-must be paid from the \$200. The good side of the "spend-down" method of qualifying for Medicaid is that elders can meet sudden, overwhelming medical expenses through Medicaid. The bad side, though, is that few people can stay at home on \$200 a month; hence they must go to a nursing home. (To enter a nursing home, a person must also have certain medical needs.)

Private insurance and personal resources (other than the Medicaid spend-down) pay only about 20 to 30 percent of nursing home costs. While many companies extend employee health care benefits to retirees, they may or may not cover nursing homes or other types of long-term care; coverage usually depends on how those policies treat Medicare.

Figure 1 illustrates a model of a comprehensive system of long-term care, which addresses the needs of elders as well as other segments of the population. The article accompanying Figure 1 (see page 67) highlights the key points on the spectrum for older persons as they actually function in North Carolina. Within this model system and the North Carolina experience, the type of reimbursement often determines the level of care. Put another way, "who pays" determines the level and location of health care on the continuum—not the more appropriate consideration: the kind of care the person needs.

Federal policy is largely responsible for this, but many state-level decisions also affect the relationship of reimbursement to type of care. What can state lawmakers, health-care administrators in and out of government, and various advocacy groups do to change how cost affects this spectrum of services? Are there true alternatives to institutionalization?

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Can We Save Money and Improve Care?

In 1981, Congress allowed states to begin three-year demonstration programs to see whether the growth of Medicaid expenditures could be curbed by development of home and community services. In states wishing to develop such programs, Congress permitted Medicaid payments for screening, case management, and other services traditionally not covered by Medicaid. North Carolina chose to participate in the federal program, which has since been extended and continues today.

Also in 1981, the North Carolina General Assembly passed House Bill 405 directing the Secretary of Human Resources to establish a screening program for people seeking long-term care. The screening was to occur before people were admitted to an institution. The law called for the program to be administered at the local level and to provide "elderly persons with the least restrictive level of care that meets the medical and social needs of the person." A nurse and a social worker (in consultation with a doctor) are to conduct the screening and arrange proper services for those persons who can and want to stay at home.

For those persons who are eligible for Medicaid, the concept goes a step further. If a person qualifies for admission to a nursing home under this screening program, that person can get into what is known as the Medicaid "waiver" program. In other words, Medicaid would waive its normal restrictions and pay for home and community-level care not normally covered.

In North Carolina, the Medicaid waiver program came to be known as the Community Alternatives Program, nicknamed CAP. The program was to include "screening, case

management, homemaker/home health aides, chore services, durable medical equipment, home mobility aids, respite care, preparation and delivery of meals, and adult day health care," according to a report developed jointly by the N.C. Health Care Facilities Association (trade group for nursing homes) and the University of North Carolina at Chapel Hill.¹¹

About 25 counties are now participating in the CAP program, says Jim Dunn, coordinator of this program for the Division of Medical Assistance, including Mecklenburg, Durham, Orange, Buncombe, Cumberland, and New Hanover counties. "Our most recent request to expand the program, however, was turned down by HCFA," says Barbara Matula, director of the Division of Medical Assistance.

Counties using the program want to keep it, says Dunn, because "we are keeping people out of nursing homes, or at least delaying entry." Though the division has no hard figures to prove cost effectiveness, federal monitors are watching the North Carolina program closely, says Dunn. Projections based on monitoring utilization of the waiver program and costs from April 1984 through January 1985 "show it (to be) cost effective," he adds.

Conclusions about cost savings remain ambiguous, however. Studies in Wake County and by the N.C. Health Care Facilities Association indicate that with Medicaid reimbursements, home-health care can cost less for some people than nursing home care. Other researchers, particularly William Weissert, insist that people in nursing homes by and large cannot be served as cheaply in a home setting, because of who they are—not because of how care is paid for (see the sidebar on page 72 for more on these studies and their findings).

Most nursing home patients stay a short time, says Weissert. Health professionals generally agree that if persons in nursing homes are to be moved to a community or home setting, these short-stay patients are the ones to concentrate on. But most nursing home beds are filled by patients who stay a long time. "If you stay three months or more, you almost never get out," says Weissert.

Helping long-term patients move back to the community offers a challenge to some health care professionals. One of these is George Stiles, executive director of the Mecklenburg County Health Care Cost Management Council, which received a \$1.5 million grant from the Robert Wood Johnson Foundation in 1985. Part of the Mecklenburg program is called PACE, Program of Affordable Care for the Elderly.

"I think long stayers are a particularly inviting target for aggressive intervention," Stiles says. "The potential payoff is high." One segment of that long-stay group is patients who were placed in nursing homes to recuperate. But they don't get moved, says Stiles, because they had to "spend down" all their resources to qualify for Medicaid, and now they can't afford to live outside a nursing home.

In the end, then, the Medicaid waiver program might reduce some nursing home costs, but for a limited number of older persons. Weissert and other researchers may well be on the right track in cautioning about the "cost-effectiveness trap."

Policy Considerations for the Future

The nursing-home-care versus home-and-community-care question does suggest one overriding conclusion. Innovative means of both controlling costs and providing needed care must be found. The discussion below, divided into four areas, explores possibilities for the future.

A. Explore new ways of paying for longterm care, such as long-term care insurance. Despite the seeming inevitability of longterm nursing home care, relatively few old people ever use it. That's why many actuaries think long-term care insurance is financially feasible, and why some companies already are marketing it.

"The premiums are surprisingly low and the benefits surprisingly extensive," covering both nursing home care and home care, says Craig Souza of the N.C. Health Care Facilities Association. Souza says coverage costs less than \$100 a month.

. Prudential Insurance Company has started marketing such a policy to members of the AARP. 12 Matula of the Division of Medical Assistance points out that Fireman's Fund Insurance Companies have had long-term care insurance for more than a decade.

By providing money to pay for longterm care, such insurance protects the elderly person from having to dispose of home, car, and other resources for care. That makes a return home from a nursing home financially possible. Long-term care insurance would emphasize returning home where all but the most infirm are better off. Insurance also would cover in-home care and home health care.

For Gary Bowers, executive director of the N.C. Association for Home Care, the question is how to encourage such insurance. "Option one is to go to the legislature and get them to mandate (health insurance companies to provide) coverage," says Bowers. A second option is to develop a model plan and then market it to insurance companies and employers.

For those elderly persons who could not afford the premium for such insurance, some experts propose innovative financing techniques, such as using home equity to pay premiums. Weissert points out that three-fourths of the aged own their own homes, 80 percent of those free and clear. The average value is \$50,000.

Other alternatives for such insurance include:

- Create Medicare Part C. People could voluntarily sign up for long-term care, and be completely covered.
- Permit Health Care Individual Retirement Accounts (IRAs), devoted to long-term care needs, with a tax credit similar to regular IRAs.
- Establish a type of HMO (Home Maintenance Organization) that is aimed at providing home services. 13
- Develop a national insurance scheme. Canada recently expanded its universal health insurance program to include long-term care, both in nursing homes and in the community.¹⁴

Physical therapy at Mayview Convalescent Home in Raleigh



- B. Examine the role of nursing homes in the long-term care continuum. This task requires answering three separate, vet intertwined, questions.
- Has the state moratorium on growth in the number of nursing home beds been too rigid so that there are too few beds?
- Is there a need for an additional level of care, called Super Skilled Nursing Facilities, between hospitals and nursing homes?
- Should hospitals pay nursing homes to take patients off their hands until Medicaid eligibility has been determined?

There are patients in hospitals who don't have to be there, but who can't get out. "We have documented the problem of hospital backup," says Stiles of the Mecklenburg Council. "Significant numbers of elderly patients who are in acute care hospitals don't need to be there ... but they can't leave because there is no place for them to go." These patients ran up \$177,000 of "unnecessary costs" in January alone at Charlotte Memorial Hospital, adds Stiles.

"The condition a man is in can best be judged from what he takes two at a time—stairs or pills."

> -Author Unknown

Most blame the state's three-year moratorium on construction of nursing home beds—a moratorium imposed to slow the rapidly rising costs of Medicaid.15 "Patients never backed up until the supply of nursing home beds became critical (during the moratorium)," says Souza. The moratorium ended in 1984. Currently, some 1,600 nursing home beds are scheduled to be added after approval by the Department of Human Resources (DHR). By 1989, another 3,000 will be authorized, increasing total nursing home beds from about 22,500 to 27,100.16

But even 27,100 appears to be low, compared to other states. According to Souza, Georgia has about 34,000 beds and Tennessee, about 29,000. He said North Carolina was among the nation's lowest in beds-perthousand persons over age. 65.17

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Cost Effectiveness Studies: How Important Are They for Long-term Care?

Experts disagree on whether cost effectiveness is an appropriate way to analyze the long-term care health system. A number of research efforts in North Carolina are testing whether money can be saved through alternatives to placing people in nursing homes.

AHEC Finds Cost Savings for Home Care

Perhaps the most notable study was conducted by the Area Health Education Center (AHEC), which is based at Wake County Medical Center and affiliated with the University of North Carolina Medical School. The AHEC project, called Care Options Program for the Elderly or COPE, conducted a two-year study on its Medicaid waiver program (see discussion of this program in the main article, page 70). The COPE study reported that for participants in the program "the cost of maintaining individuals in their homes was 36 to 40 percent of Medicaid nursing home costs."1

The COPE project had a test group of 201 persons. All 201 met screening requirements for admission to a skilled nursing facility (SNF) or an intermediate care facility (ICF). Of the 201, however, only 101 qualified for the Medicaid waiver program and hence were included in the COPE group. The other 100 were not in the COPE group, usually because they could not qualify for Medicaid. Hence the 201 persons in the study fell into four groups: 1) 58 in the COPE group, SNF-eligible; 2) 43 in the COPE group, ICFeligible; 3) 39 not in COPE, SNF-eligible; and 4) 61 not in COPE, ICF-eligible.

During the project, only 13 percent of the COPE group went into nursing homes

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Nationally, an additional 169,000 nursing home beds will be needed by 1990, says Robert Van Tuyle, chairman of Beverly Enterprises, the nation's largest nursing home chain. 18 But he doesn't expect that many to be built because of state limits on new construction. "Severe limitations on capacity make it obvious that available beds will be reserved for the sickest patients," says Van Tuyle. He and other industry leaders see development of home health care and retirement living complexes as two likely results.

Despite Van Tuyle's claim that nursing homes will concentrate on treating the sickest patients, people who require extra care are having difficulty finding beds in North Carolina. Here's why: Heavy care patients require substantially more staff time. Under reimbursement rules, nursing homes get paid the same for these patients as they do for average patients. Too many heavy care patients may force a nursing home to hire additional staffers with no increase in medical reimbursement.

One possible solution is the Super Skilled Nursing Facility (Super SNF), a new level of care between a hospital and an SNF nursing home, which would concentrate on heavy care patients in return for a higher rate of reimbursement. "Super SNF was an idea to solve the problem of hospital backup," says Stiles. 19 An alternative solution, which would require no new institutions, is simply to reimburse nursing homes more for heavy care patients. 20

Other health officials believe that the shortage of nursing home beds can be addressed by utilizing another section of the long-term care continuum—rest homes. While rest homes are not supposed to provide health care, home health nurses can treat persons in rest homes. The shortage of beds resulted from blinders, says Donna Nixon, formerly of the N.C. Division of Aging. "We don't have to build any additional nursing home beds," she says. Instead, she suggests using the 3,000 empty rest home beds and treating the patients with home health nurses.²¹

Because of the moratorium on nursing home beds, rest homes are playing a more prominent role in the long-term care continuum in North Carolina. Rest homes, which are administered at the state level by the Division of Social Services, are increasingly accepting persons who have specific health-related needs, even though rest homes are not supposed to provide health care.

Preliminary findings from a study still in progress by the Mecklenburg Council suggest that the shortage of nursing home beds and heavy care patients are only part of the hospital backup problem. A third problem is determining Medicaid eligibility, which typically takes 45 days. Medicaid caseworkers are "overwhelmed with applications," says Paul Beck of the Wake County Area Health Education Center (AHEC), which coordinated the county's Medicaid waiver program for two years. The caseworkers take applications "in chronological order. If a patient is in the hospital, he continues to sit in the hospital," says Beck.

Medicaid has become, in large part, a health insurance program for older persons.

Nursing homes are often unwilling to accept Medicaid-dependent patients from a hospital until they become eligible for Medicaid—"understandably so," says Stiles of the Mecklenburg Council. In the council's initial study of hospital backup, the apparent reason for the backup for a significant number of patients was that they had not yet been determined eligible for Medicaid, says Stiles.

One way to address the slow Medicaid process is for hospitals to actually pay nursing homes to take these patients while awaiting Medicaid eligibility. Weissert of UNC suggests that hospitals could save money under such a system. Most of these patients are beyond the point where Medicare will pay (under the DRG specifications), so hospitals are paying for the care from the hospital resources anyway. Moreover, most such patients will eventually become eligible for Medicaid. Nursing homes would repay the money when Medicaid starts paying.

C. Consider more formal interagency cooperative agreements or reorganization. Five divisions of the N.C. Department of Human Resources (DHR) share responsibil-

ity for long-term care of older persons: Social Services, Facility Services, Medical Assistance, Aging, and Health Services.²² No one is looking at the broad picture, says Beck of the Wake AHEC. Specifically, an older person has difficulty moving from one level of care to another along the continuum without having to apply to two or three agencies.

Some state health officials agree. Maola Jones, acting head of state health planning, for example, says coordination of services "is the biggest problem. Some of the barriers will have to be removed," says Jones, "so a person does not have to go through a whole lot of applications." A task force based in former DHR Secretary Sarah Morrow's office worked to enhance coordination among these agencies. But little has come of the effort.

"I honestly believe we have to bite the bullet," says Nixon. "We'll never have a program that works unless it is pulled together at the top."

Such sentiment does not necessarily mean consolidating functions now in several divisions. In fact, some believe that having different divisions responsible for various elements of the long-term care system is better because they serve as a check and a balance on each other. "I would not like to be licensed, governed, and paid for by one group," says Souza of the N.C. Health Care Facilities Association. "But I would like to see more coordination."

Some officials believe the coordination issue rests primarily at the federal level. "Scattered state administration reflects scattered national policy and funding sources," says Barbara Matula. "It isn't enough alone to pull together these state functions. What's needed is to have a cohesive federal funding policy that identifies sources of federal funds and fills the gaps in the continuum of care."

One effort at better coordination is using case managers. Under the Mecklenburg Council, for example, case managers are working out of private group practices and at hospitals to try to reduce the need for institutionalization. The case managers can make sure patients have support when they need it. This support includes helping the patient determine which agency to deal with.

Current DHR Secretary Phil Kirk is also interested in the case manager system. Kirk's office is now exploring options regarding the single portal of entry concept, which is similar to the case manager approach.²³

D. Expand the effectiveness of home care by providing support programs for caregivers. John Horn lives at home in Charlotte instead of in an intensive care unit of a hospital—too sick even for a nursing home. He is as dependent on his wife and two daughters as he is on his respirator. Horn is lucky to have three care-givers to share the burden of 24-hour-a-day monitoring of the respirator for an alarm. Having three family members rotate responsibilities for John, however, requires that all three of them learn how the machine works and other essential care-giving tips. There are at least two important issues here, then: burnout of a care-giver and proper training.

A breakdown in the care-giver—not in the person being cared for—is the biggest single reason for institutionalization, says Stiles of the Mecklenburg Council. The caregiver decides, "I can't do this anymore." Two types of support for care-givers can help respite care and support groups. In support groups, care-givers can discuss common problems and perhaps get relief from their own anxieties by realizing that others have similar problems. Also, group members can try common solutions. Respite care is extremely important as well. It allows families to get away for holidays and vacations and feel secure that an elderly parent is getting proper care.

Conclusion

R espite care and support groups might indeed help John Horn stay at home, despite his damaged lungs. But this is only one piece of a complex puzzle. Health care—from hospitals to home respirators—has evolved into a vastly expensive and fast-changing system. Meanwhile, more of the population is reaching old age, even as the miracles of medicine extend the lifespan.

The long-term care continuum has grown wider and now includes options that few could have imagined just decades ago. But as the range of options has expanded, two interlocking complications have arisen and won't go away: First, who will pay? And second, what kind of care is most appropriate for each person?

The home-health system has already helped John Horn stay at home. But he depends totally on a support system that begins with his family and medical apparatusand includes a home-health nurse and other assistance. John Horn is just one of the 700,000 North Carolinians over 65. Many are robust and entirely independent, but others are more dependent, just as Horn is. Moreover, those older persons who are sick or require assistance in living take an enormous chunk out of the health care resources. Medicaid has become as much a way to pay for medical care for old people as for poor people, the original purpose of the program.

One health care official, in an interview for this article, called the issue of long-term care for the elderly the second biggest problem facing society—behind nuclear war. Some would say she exaggerates, but few would quibble with the direction of her sentiment. How this country—and this state—address the interlocking and challenging issues in long-term care will in the end affect us all.

FOOTNOTES

¹Dr. William R. Hazzard sees the "increasing probability of physical, mental and social dependency" as an "inevitable present consequence of survival into old age." In an August 1983 paper in Postgraduate Medicine (Vol. 74, No. 2) and at a 1985 Duke University conference on age and the prevention of age-related disorders, Hazzard says: "While aging per se cannot be prevented, many of its attendant disabilities can be forestalled until the upper limit of the human life span (about 85 years) is approached." Hazzard, director of the program in gerontology and geriatric medicine at Johns Hopkins University, sees a time not far ahead when virtually all the causes of death save accidents will be eliminated. "In such an ideal state, the death rate would be extremely low except near the upper limit of the human life span, when it would be very high indeed. One estimate of the average longevity in that optimal state is 85 +/- 4 years. One in 10,000 individuals would live to be more than 100 years of age, and virtually no one would survive beyond 110 years."

²Hazzard says that in the era when everybody lives the maximum, "the specific causes of death ... would be hard to identify (as is currently often the case with the very old). Multiple vulnerabilities in interacting organ systems result in a catastrophic decline in homeostasis and death proceeds from a combination of forces ... rather than from a single, clearly identifiable cause."

³"Long Term Care in North Carolina, a continuum of services to the elderly and disabled," a pamphlet by the N.C. Department of Human Resources, February 1985.

⁴William G. Weissert, "Home and Community Based Care: The Cost Effectiveness Trap," *Generations*, Summer 1985, page 47.

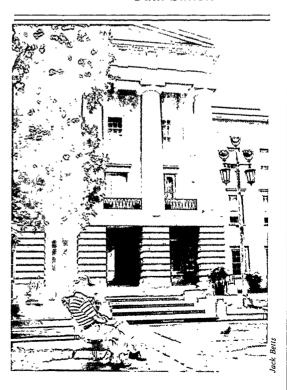
⁵Information on Medicare and Health Insurance for Older People, American Association of Retired Persons, no date.

⁶For instance, see the AARP's Medicare Supplement Portfolio. Though the pamphlet boasts of increased benefits for 1985, each of the three plans carefully says: "Note: Eligible charges are determined by Medicare. Your doctor may charge you more." Similar language appeared in other plans, such as National Home Life Assurance Company's Basicare 65 and Secure Care Plus, Colonial Penn Franklin Insurance Company's Maturity 65 plan, and Union Fidelity's Medicare Part B Supplement Rider. Some use potentially misleading language such as "we pay benefits for the eligible in and out hospital surgeon's fees not payable by Medicare," which means just those that meet the Medicare definition of reasonable. Some others, such as Union Fidelity's Medicare Supplement Plan, don't even touch doctor bills. Most of the plans carefully exclude coverage of pre-existing conditions too, which is variously described as sickness or injury treated between six months and a year before the date the policy goes into effect, and extending for three to six months after the policy takes effect.

⁷"Personal Perspective," Business and Health, May 1985, page 60. Howard is also president-elect of the Federation of American Hospitals, which represents 1,200 investor-owned hospitals and health care systems.

⁸In Fiscal Year 1983, those in skilled nursing facilities receiving Medicaid paid 17 percent of their bills with personal resources before Medicaid kicked in. Those in intermediate care facilities receiving Medicaid paid 23 percent of their bills with personal resources before Medicaid kicked in.

"Old friends, old friends.
Sat on their park
bench like bookends."
— Paul Simon



9For a full explanation of how Medicaid funding works, see "How Medicaid Cuts Are Calculated" by Leslie Winner in North Carolina Insight (Vol. 4, No. 4), December 1981, page 46.

¹⁰Chapter 675 of the 1981 Session Laws (HB 405), now codified as NCGS 143B-181.6.

11 Executive Summary, Service Innovations in Nursing Homes, prepared by the N.C. Health Care Facilities Association in cooperation with the Health Services Research Center and the Department of Health Policy and Administration, University of North Carolina at Chapel Hill, under grant #18-P-98188 of the Office of Research of the Health Care Financing Administration, released October 1984.

¹²See Hospitals, March 1, 1985, page 66, for a discussion of this plan.

¹³An experimental program, called Homeward, is being tested by Lutheran Health Systems of Fargo, N.D., according to a report in the April 26, 1985 issue of Modern Healthcare called "Providers will offer care in new settings." The program will-for a fixed, prepaid fee-provide skilled nursing care, intravenous therapy, home delivered meals, and other services at home.

For more on HMOs, see "Health Maintenance Organizations Arrive in North Carolina" by Robert Conn in North Carolina Insight (Vol. 7, No. 3), February 1985, page 58.

14"The Feasibility of Universal Long-Term Care Benefits, Ideas from Canada," Rosalie and Robert Kane, The Rand Corp., New England Journal of Medicine, May 23, 1985. The article summarized these points:

- availability of community services did not reduce the demand for nursing home beds;
- for a relatively controllable cost of about 10 percent of the nursing home budget, the government can provide a good quality program of home health services; and
- residents do not need to impoverish themselves and their spouses to obtain nursing home care.

15Chapter 1127, Section 31 of the 1981 Session Laws (October 1981 session).

16For the 1,600 figure, see 1985 State Medical Facilities Plan: A Component of the North Carolina State Health Plan, N.C. Department of Human Resources, Division of Facility Services, 1985, page 131. For the 3,000 figure, see Draft-1986 State Medical Facilities Plan: A Component of the North Carolina State Health Plan, July 3, 1985, page 83.

¹⁷He and his associate, Katherine McLeod, quickly add that definitions of nursing home beds and rest home beds vary from state to state. North Carolina, they said, defines intermediate care beds conservatively, which means fewer beds here are called nursing home beds. Curiously, the National Master Facility Inventory lists North Carolina as having 32,000 nursing home beds, about 10,000 more than are counted under the state's licensing law, according to Katherine McLeod. Before the moratorium began, there were 22,644 SNF and ICF beds officially recorded in the state, including beds in 15 hospitals and 220 freestanding facilities, she said.

While comparisons are difficult in beds-per-thousand because of different classification systems among states, these population comparisons provide some guideposts: North Carolina (6.0 million), Georgia (5.6 million), and Tennessee (4.7 million).

¹⁸"Long-term care industry develops alternatives to meet needs of elderly," Modern Healthcare, April 26, 1985, pp. 59-61.

¹⁹Most experts believe a Super SNF level of care could be opened without asking the General Assembly for permissive legislation. One way might be under the Medicaid waiver program. Few question that the Department of Human Resources could issue licenses under existing statutes.

²⁰That's not as easy as it sounds, say reimbursement experts. The present reimbursement presumes a mix of heavy care, normal care, and even lighter care patients (who are getting ready to move to intermediate care or go home). Would the establishment of a "heavy care" rate mean that normal reimbursement should go down? Would two separate rates mean a huge new bureaucracy to make sure nursing homes weren't trying to claim a heavy care rate for patients who just needed a little more care?

²¹The Division of Social Services estimates there are 3,000 empty rest home beds, although no exact figures are available.

²²The major responsibilities for the five divisions, regarding the long-term care system for older persons,

- Social Services: Lead agency at state level for long-term care screening program. Develops policy and guidelines for programs including adult day care, chore, homemaker, preparation and delivery of meals, housing and home improvement, transportation, and placement of adults in domiciliary and nursing care facilities. Responsible for standards for licensure of domiciliary care facilities. County departments of social services provide these services to the elderly to enable them to stay at home as long as possible, assist with placement in domiciliary and nursing care facilities, and determine eligibility for Medicaid.
- Facility Services: Writes state health plan, which spells out the state's need for long-term care services. Operates the certificate of need program. Licenses hospitals, nursing homes and other long term care services.
- Medical Assistance: Runs the state Medicaid program. Pays for health care for persons whose income is below a certain level or whose medical expenses reduce income to that level. Pays hospital and doctor bills, nursing home care, some home health care, and prescriptions.
- Aging. Operates the long-term care ombudsman program, nutrition services (including the home delivered and congregate meals programs, senior center services, and technical assistance for a variety of programs for the elderly.
- Health Services. Monitors home health care and provides financial assistance to home health agencies for patients unable to pay for essential home health services. Works on health promotion and disease prevention.

²³For more on the single portal of entry concept, see "Mental Health Policy Questions Under Debate" by Roger Manus and Michael Matros, North Carolina Insight, Vol. 7, No. 1, page 48.