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The National Council on the Aging

Fax

To: Theresa Jones

From:

Howard Bedlin

Fax: 456-5557

Pages:

2

Phone:

Date:

11/3

Re: Meeting Request

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MEMORANDUM

TO: Theresa Jones
FR: Howard Bedlin, NCOA Vice President for Public Policy and Advocacy
RE: Discussion topics for requested meeting with Chris Jennings
DA: November 3, 1998

I hope to have the opportunity to meet with Chris on Tuesday the 10th from 4-5pm in order to discuss the following topics:

- The desirability of conducting demonstration projects/pilot programs to test the effectiveness of "Medicare Consumer Coalitions," which we believe to be a linchpin for successful Medicare Reform. NCOA will be releasing a feasibility study on the concept in December;
- Issues and options for improving Medicare prescription drug coverage, particularly in light of recent Medicare HMO non-renewals;
- Options and opportunities for home and community-based care incremental reform; and
- General strategies and questions surrounding the Bipartisan Commission on the Future of Medicare. As Chair of the Leadership Council on Aging Organization's Health Committee, I am interested in exploring opportunities for the coalition to play a productive role in influencing the Commission's efforts.

Thank you for your consideration. Please contact me at 479-6685 to let me know if the meeting can take place.

Rough Crossings: Family Caregivers' Odysseys through the Health Care System

Carol Levine
Director, Families and Health Care Project

United Hospital Fund of New York

Executive Summary

Each year more than 60 million Americans are admitted to or discharged from health care facilities. For institutions, these entries and departures are routine processes; for patients and their families, they are often fraught with anxiety and fear. This special report explores these transitions from the unique perspectives of family caregivers—the unpaid relatives, partners, or close friends who either provide direct care and emotional support to, or manage the health care of, those who are chronically ill or disabled. Its purpose is to contribute to the development of responsible and reasonable ways to respect, understand, and help all families coping with serious illness and the major transitions that mark that journey.

SOURCES OF INFORMATION FOR THE REPORT

- Section I. Academic literature on transitions in illness and family caregiving.
- Section II. Six focus groups of family caregivers which the United Hospital Fund's Families and Health Care Project convened in New York City in September 1997.
- Section III. Planning grant applications submitted by 28 New York City hospitals in April 1998 to the United Hospital Fund's Family Caregiving Grant Initiative, established to help New York City hospitals develop and test programs to respond to caregivers' unmet needs.

SECTION I. ILLNESS, CAREGIVING, AND TRANSITIONS

- Caregiving transitions occur in the context of the progression of a disease. While clinicians treat and classify the stages of disease, patients and families experience the symptoms, suffering, and changes brought about by illness.
- Caregiving can be considered to be a "career," replete with myriad stages, transitions, and stresses, which place caregivers in a state of constant flux.
- Caregiving can be seen in the context of a family's life cycle. A serious illness interrupts common transitions such as births, launching young adults, marriage, and retirement, and requires that families adjust to the anticipation of further disability and untimely death.

- Any transition from one health care setting to another, therefore, adds a complex layer of adjustment to the transitions already underway in a caregiver's family and his or her experience of illness.

SECTION II. CAREGIVERS' VOICES

The focus groups produced remarkably consistent themes, especially in terms of caregivers' feeling unprepared for caregiving tasks. The conversations provide insights into caregivers' individual experiences, and have direct implications for improving the health care system and for creating smoother transitions between care settings.

Family Ties

- Caregivers were usually thrust into their role by necessity, although most wanted to provide care because the ill person was significant in their lives.
- Caregivers whose family members and friends shared the burden of caregiving fared better than those who provided care alone.
- Caregivers' emotional attachment to their loved one was a powerful motive for providing care, but also led to anxiety and fear about the patient's welfare.

Caregivers' Reactions to Changes in Illness and Care Settings

- Transitions can be traumatic because they are often times when caregivers first become aware of changes or deterioration in the patient's condition. Many times they feel a heightened, even overwhelming, sense of personal responsibility for the patient's health and well-being.
- Many caregivers spoke of their sadness and the loss or change in their relationship with the care recipient.

Going Home

- Caregivers experienced discharge from the hospital as an abrupt, upsetting event because hospital staff failed to prepare them technically and emotionally for changes in the patient's condition. Many felt abandoned at a critical time.

Admission to a Hospital or Nursing Home

- Although most of the discussion centered on transitions from institution to home, the reverse—transition from home to hospital or nursing home—also presented problems.

- Many caregivers fear that their loved one will be neglected in hospitals and nursing homes. A transition to an institution means extra vigilance for the caregiver.
- In general, participants reported that hospital staff failed to acknowledge their emotional needs. None of the participants said that health care professionals had referred them to community-based agencies for emotional or other kinds of support.
- Many caregivers believe that older people are not treated sensitively in hospitals.
- Caregivers want compassion and understanding from institutional staff, and they want to be able to communicate with health care professionals about their loved one's condition.

Culture, Family Structure, and Religion

- Caregivers reported that cultural differences created special care needs, and sometimes led to problems with health care professionals whose backgrounds differed from those of the family.
- Some caregivers who are not immediate family members, or who do not fit into the traditional definition of "family," reported having difficulties obtaining information from, and being acknowledged by, hospital staff.
- Although some participants sought a religious explanation for their situation, no one mentioned organized religious institutions or clergy as a source of solace or assistance.

Financial Factors

- In most groups, discussion centered more on the emotional aspects of caregiving transitions, and less on financial concerns.
- When discussion did turn to financial issues, participants criticized the health care system's focus on costs, and spoke of needing more resources to provide care.

Death and Dying

- Bereaved caregivers did not have markedly different caregiving experiences from current caregivers, but they experienced the additional stress of what they felt was inappropriate care at the end of their family member's life.
- Most bereaved caregivers were either unaware of hospice or felt that it was an inappropriate choice for their family member.

SECTION III. HOSPITALS' PERSPECTIVES

The applications submitted by 28 New York City hospitals to the Family Caregiving Grant Initiative demonstrate that hospitals are beginning to recognize the tremendous burdens upon family caregivers. Their comments both confirm and amplify many of the themes articulated in the focus groups.

General Themes

- The health care system fails to adequately support and train caregivers.
- Fragmented communication leaves caregivers confused and uninformed.
- Discharge planning, as currently practiced, often fails to create smooth transitions.
- The health care system does not sufficiently recognize the role of family caregivers.
- Patients from diverse backgrounds have different needs and circumstances.

Barriers to Serving Family Caregivers

- Hospitals lack the time and financial resources necessary to address caregivers' needs.
- In their focus on the patient's clinical condition, health care providers often overlook the caregiver.
- Information systems fail to collect and share facts about the social and emotional aspects of care.
- Language, cultural, and educational differences can create challenges when families and health care professionals come from different backgrounds.
- Families' emotional responses to illness can make it challenging for hospital staff to provide support in a meaningful way.

These applications suggest that, at least at some administrative and clinical levels, professionals want to do better, and recognize the substantial barriers to improvement that they face.

SECTION IV. RECOMMENDATIONS FOR CHANGE

The following recommendations for change are a beginning. They are not so grandiose that they depend on vast changes in the American political or economic system nor so trivial that they accomplish little more than a token bow to family caregivers. These recommendations, in conjunction with the Guiding Principles for Effective Partnerships between Family Caregivers and the Health Care System (see Appendix B), can make a difference and should be implemented

Recommendation 1: Health professionals, government agencies, and managed care organizations should recognize explicitly, in policy and practice, that family caregivers who assume significant care responsibilities are a valuable but vulnerable resource.

Recommendation 2: This recognition of the critical role of family caregivers must be built into medical, nursing, and social work training and continuing education.

Recommendation 3: More research is urgently needed to understand the impact on family caregivers of changes in the health care system and on interventions that families need and want.

Recommendation 4: Health care providers must make discharge planning, and transitions from one care setting to another, a process rather than a single event. The outlines entitled "Covering the Basics for Family Caregivers" (Section V) provide a good start toward creating smoother transitions. They are designed for use by both health care professionals and family caregivers, and should be adapted to fit individual circumstances.

Recommendation 5: Hospitals and other health care institutions should develop model programs that offer innovative ways of involving and meeting the needs of family caregivers.

Recommendation 6: Public and private insurance plans and managed care organizations should evaluate benefits and service plans to reflect the importance of training, supporting, and communicating with family caregivers.



**United
Hospital Fund**

Shaping New York's Health Care:
Information, Philanthropy, Policy.

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Testimony of Carol Levine
before the U.S. Senate Select Committee on Aging

September 10, 1998

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Good morning. My name is Carol Levine and I am Director of the Families and Health Care Project at the United Hospital Fund in New York City. Since its founding in 1879, the United Hospital Fund has been devoted to shaping positive change in health care delivery and financing. The Fund works through philanthropy, research, and program and educational development.

Thank you very much for inviting me to testify before you today on the important issues facing family caregivers. In convening this hearing, the U.S. Senate Select Committee on Aging has taken an important step in increasing the awareness of policy makers, health care professionals, and the general public about the critical role of family caregivers in the well-being of our nation's elderly people, and those who are chronically ill or seriously disabled, whatever their age. I am delighted to be able to introduce at this hearing a new special report from the United Hospital Fund called "Rough Crossings: Family Caregivers' Odysseys through the Health Care System." The entire report has been provided to supplement my testimony.

The Importance of Transitions

The report focuses on transitions -- patient moves to and from hospitals, nursing homes, or rehabilitation units -- and how these transitions affect family caregivers. The main source of information was a series of six focus groups held in New York City with 56 experienced family caregivers. The caregivers were a very diverse group, including men as well as women, people with many different ethnic backgrounds, educational levels, family incomes, and ages. The caregivers ranged in age from 20 to 70, with the majority in their 30s and 40s. Many held jobs,

although some had been forced to leave employment to take care of their family member. The care recipients were mostly women between the ages of 60 and 80 with multiple serious health conditions.

At the beginning of the hearing you saw and heard on video three of these caregivers talk about their lack of preparation for the task, their anxiety about taking proper care of their loved one, and the isolation that comes with long-term caregiving.

* "The first night she came home from the hospital we went to bed and I found that she was incontinent and that her bandages were oozing. No one had told me what to expect. I didn't know who to be angry at or who to call to help me take care of her."-- A husband whose 71-year-old wife has multiple sclerosis and had extensive surgery for a bone infection

* "I was terrified. My generation doesn't know about computers. They put in a feeding tube and showed me --- 1,2,3 -- how to use it. But I was expected to be responsible for it at home." -- A wife whose elderly husband has had several strokes.

Here is another voice, which is not on the video you saw.

* "I had to fight through layers of bureaucracy for ten days to get a dangerously unstable hospital bed replaced at home. Then when the bed arrived -- without notice, in the evening when there was no one to help me move him -- it turned out to be the wrong bed."-- A wife who takes care of her 70-year-old husband left quadriplegic and brain-damaged after an automobile accident 8 ½ years ago.

The last voice is mine. Like the caregivers in our focus groups, I am one of the more than 25 million other family caregivers who are struggling with the fragmented, inflexible, and

increasingly complicated collection of institutions and agencies called "the health care system."

I joined the United Hospital Fund in October 1996 to create the Families and Health Care Project after a long career in health policy and medical ethics, which included being awarded a MacArthur Fellowship for my work in AIDS policy. Yet nothing in my professional background, or my experience as a mother of three children, had prepared me to be the caregiver for a severely disabled, brain-injured husband.

Why Systems Must Change

Professionals call us "informal" caregivers to distinguish us from paid workers, implying that there is something casual and nonessential about our care. Because we love the people we take care of, we do not ordinarily see ourselves as anything but spouse, child, sibling, partner, friend. In fact, we take care of the basic health, social, and emotional needs of people who are disabled or chronically or terminally ill, and who are only sporadically hospitalized. Sometimes we have to make our homes into mini-hospitals, crowded with high-tech equipment we operate and monitor. In the past few years the health care system has changed dramatically. Cost-containment has shifted responsibilities to patients and families in unprecedented ways. This hearing is an important step in looking at that impact systemically.

Despite the near-universality of caregivers' experiences, our stories will remain just individual anecdotes that evoke sympathy, shock, or avoidance until the health care system begins to change. And it is the system that must change. This is a potentially revolutionary idea.

Today, the formal health care system expects family caregivers to change, to accept its

irrational and often contradictory array of rules and regulations, the pervasive lack of communication and information, and inadequate training and follow-up. Even much of the family caregiving self-help literature focuses on "coping" -- learning how to live with an intolerable situation by changing one's own attitude and expectations. Coping skills are important, but there are limits to what even the most successful copers can sustain. Martyrdom--or indeed heroism--is not an ethical or practical standard for public policy or health care practice.

The devastating results of the health care system's lack of attention to family caregivers can be seen every day. Middle-class families who thought they had comprehensive health insurance are being impoverished by caregiving, since much of what they need at home is not deemed "medically necessary" by insurers or falls under the unreimbursable category of "custodial care." There are well-documented mental and physical health risks to caregivers. Employers face productivity loss and absenteeism when valuable workers juggle the competing demands of job and caregiving. Without support and guidance, families can be irreparably torn by dissension. Divorce is not uncommon; suicide not unheard-of. Other family members, children in particular, may be denied the care and attention of the caregiver preoccupied with the ill person.

What can be done to encourage and require the health care system to change? There is no single solution, no law or regulation that will by itself make a difference. In a long-term agenda, high priority should be given to building an understanding of the needs of family caregivers into medical, nursing, and social work education. But several important steps can be taken now.

United Hospital Fund Initiatives

* The United Hospital Fund has already added family caregiving to its philanthropic and research agenda. The very existence of a project like mine in an organization with "hospital" as its middle name is evidence of the growing awareness that it is in institutions' economic interests as well as humanitarian missions to understand and address the needs of family caregivers. Studies show that even modest, targeted attention to family caregivers can prevent or delay costly hospital readmissions or nursing home placement.

* The Fund commissioned Peter Arno to develop the first systematic estimate of the economic value of informal caregiving. He presented the sobering results to you today.

* The Families and Health Care Project prepared a series of guiding principles to promote effective partnerships between health care professionals and family caregivers. These too are included in the special report, "Rough Crossings."

* The Fund has embarked on an ambitious three-year \$1.3 million grant initiative to change the way hospitals work with family caregivers and other health care providers. In its first phase, 16 New York City hospitals were awarded planning grants to gather and analyze information about family caregivers. Dr. Mary Mittelman, my co-panelist, is one of the grantees. In February we will award about six two-year grants of \$150,00 to \$200,000 each to test model interventions to change hospital practice and procedures.

* In the coming year we will be embarking on other activities that build on our initial work, and we will continue to join in collaborative efforts with the many active consumer and health care groups that are already dedicated to improving services for family caregivers.

Recommendations

Of course we cannot meet this challenge alone. For our colleagues in health care and for policy makers at all levels we offer several suggestions for program review and development. The key elements are family caregiver involvement, information and communication, training and education, and a variety of support services. Specifically,

** Hospital staff should make discharge planning and transitions between home and hospital a process, not a last-minute, one-time event.* "Rough Crossings" contains not only experiences of caregivers, but also the perspectives of hospital staff as well. Health care professionals confirmed what family caregivers stressed--that discharge planning, as currently practiced, often fails to meet the needs of family caregivers. Most discharge planning focuses on who is paying for what, leaving the family caregiver to sort out an often confusing array of medications, machines, and instructions. Many caregivers felt abandoned at a critical time. If managed care is to fulfill its promise, it must truly be care management, not just cost containment.

Our report contains a series of outlines called "Covering the Basics for Family Caregivers." They are lists of items to discuss when planning for different situations, when the patient is in the hospital, for example, or prior to discharge, or when the patient is terminally ill. We suggest that these outlines can be practical guides for health care providers and family caregivers to start an ongoing discussion.

For these or any other discussion aids to be effective, however, there must be

appropriate services and training in place. Thus, our next recommendation:

* *A high priority should be given to developing a broader array of programs that support family caregivers.* There are not enough counseling, support, and respite services for the many different types of caregivers and their special needs. Some excellent programs exist but many caregivers do not know what is available or where to look for help. None of the caregivers in our focus groups reported a professional referral to a community-based agency for further assistance, counseling, or information. Some eventually found such an organization on their own.

* *Health care professionals should be assertive advocates for family caregivers.* As one of our basic principles states, professionals have responsibilities toward family caregivers who provide, monitor, and manage their patients' care at home. Resourceful and willing though they may be, family caregivers need advice, expertise, and especially advocacy from those who know the ins and outs of health care bureaucracies.

* *Insurers and their subcontractors should be held to a high standard of performance and accountability.* In a hospital my husband's unsafe bed would have been replaced immediately, if for no other reason than concerns about liability. Institutions have clout; individual family caregivers have little. Managed care companies and insurers frequently set up barriers to immediate service and limit choices of equipment vendors and other service providers. Family caregivers need a simple, systematic way to report poor service and bureaucratic hassles; and they are entitled to a timely response.

* *Insurers and public program administrators should recognize that communicating with*

family caregivers is essential to quality patient care. Even the most dedicated clinicians cannot spend the necessary time communicating with family caregivers unless they are reimbursed adequately. The simplest intervention -- listening to family caregivers and assisting them to do the hard job they have lovingly taken on -- may be the most critical.

Finally, what can policy makers, especially at the federal level, do?

I believe that the single most important change in federal and state policy is an explicit recognition of the critical role of all family caregivers in the health care system, not just those whose care recipients receive services from Medicaid or Medicare. This implies a recognition of the links between the "public" and "private" sectors. Public policy decisions on programs like Medicare and Medicaid set the basic framework for the private sector in terms of service development and availability, criteria of "medical need," wages in the labor market, and so on. To look at it positively, an emphasis on serving family caregivers in the public sector will have an important carryover into the private sector where managed care companies increasingly determine benefits. Private foundations have an important role as well in supporting innovation, evaluating new programs, and stimulating research.

A Family Impact Statement

Furthermore, health and social service policy decision making should include a family focus. I suggest that a "family impact statement" should accompany major policy decisions. We expect the same for the environment and for paper reduction. Aren't the people who are the bedrock of the health care system equally important?

One specific example is the hospice benefit under Medicare. Hospice is one service that is based on the importance of the family unit and offers ongoing support as well as a bereavement and follow-up service. But hospice also relies heavily -- more heavily than most people realize -- on the direct care provided by family members. Efforts to contain hospice costs have had a chilling effect on admission to hospice. This in turn has a serious impact on family members who have been caring for a seriously ill loved one for long periods and who look to hospice for assistance in the final months of intense caregiving. Here is one program where a "family impact" statement would help define the context in which efforts at containing costs and eliminating fraud take place.

Policy makers at all levels have long been ambivalent about family caregivers. Yes, they say, they are important, and we certainly don't want them to give up because that will add to the public burden. But no, they hasten to add, we don't want to do too much for them because of the "woodwork" effect. The "woodwork" effect suggests that once given a chance for some relief, family caregivers would come out of the "woodwork," like so many unwanted insects, with greedy appetites for resources. Speaking for myself, I am not part of the woodwork. I am part of the foundation on which our health care system rests. And if the foundation collapses, the entire structure is endangered.

What do family caregivers themselves say they want? In the twelve hours of caregiver conversations in our focus groups, and in countless other conversations: this is what I have heard again and again: "Someone to talk to who understands what I'm going through." "Someone to call when I have questions." "Technical training that recognizes my emotional involvement with

the patient." "A day off." "A kind word from a doctor or nurse or social worker."

These are hardly overwhelming demands. Meeting such modest requests would be a strong beginning to humanizing our health care system for patients, families, and professionals alike.

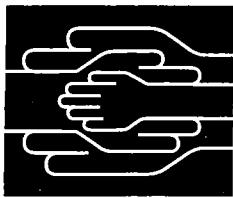
Thank you again for the opportunity to speak to you today. I will be happy to answer any questions.

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Financing Long-Term Care: An Intragenerational Social Insurance Model

Yung-Ping Chen

Financing long-term care (LTC) has become an increasingly significant public policy challenge because of a confluence of factors. These factors juxtapose the expanding numbers of older people, particularly the very old, against public and private resources that are growing at a much slower rate. This article proposes a new paradigm—the use of an intragenerational social insurance program that I call “Social Security/Long-Term Care”—to provide a basic level of long-term care protection.

Traditional pay-as-you-go social insurance programs, such as Social Security and Medicare, are built on the bedrock of intergenerational transfers. This works well when the population and economy are growing to the extent that, over a long period of time, taxes paid by workers and their employers are at least or more than keeping pace with benefit payments to retirees and other beneficiaries. Currently, however, these programs are showing financial strain as a result of slow economic growth and the aging of the population.

The Long-Term Care Population

The continued graying of America and the growth in the number of the oldest old have important implications for LTC services and financing. The number of those aged 65 and over constitute approximately 13 percent of the total population, and are expected to reach 18 percent by 2020 and 22 percent by 2030. The number of those over age 85 is expected to double between 1990 and 2030. While one study suggests that there may be emerging a reduction in age-specific disability rates (Manton, Corder, & Stallard, 1993), such a development still will not significantly reduce the elderly's aggregate need for

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LTC Choice: A Simple, Cost-Free Solution to the Long-Term Care Financing Puzzle

Stephen A. Moses

Long-term care (LTC) in the United States is more than a challenging public policy problem. It is a fascinating puzzle, as well. In fact, the question, “How will we pay for the needs of a rapidly aging population?” raises a whole continuum of conundrums. For example, why does a prosperous nation like ours warehouse its World War II generation in welfare-financed nursing homes? Why are most Americans in denial about the risks of LTC when the media warn us constantly about an impending demographic Armageddon? Why do we agree on so many of the problems and solutions of LTC service delivery and yet fail year after year to initiate decisive corrective action? This article answers these questions, solves the underlying puzzle, and proposes an affordable public policy solution.

Conventional wisdom and scholarly consensus agree: America faces a potentially cataclysmic LTC financing crisis in the foreseeable future. The evidence of impending danger lies everywhere we look: undeniable trends in aging demographics; reduced availability of informal caregivers; doubts about the quality of formal LTC; inadequate supply of low-cost home- and community-based services; rapidly escalating nursing home expenses; poorly structured delivery systems; dwindling public finances; increasingly resistant taxpayers; declining ability or willingness of families to pay privately for LTC; cracks in our public and private pension systems; and the approaching retirement of the baby-boom generation. These are the elements of consensus on the problem.

Just as the public and the experts have come to agree on the problems, they also concur on the architecture of an ideal LTC system. Certain optimal features show up consistently in task force reports, think tank studies, policy papers, and published articles. These include generous eligibility for as-

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Stats & Facts

The Growth of Assisted Living Facilities

Figures

Benefits Typically Offered in Assisted Living Facilities

Population Projection for Patients at Least 85 Years of Age

Average Daily Costs of Care Facilities

New Seniors Housing Construction

Text

Assisted living facilities (ALFs) are important new residential options in the long-term care environment. It is estimated by one survey that more than 12,000 ALFs exist today, comprising 700,000 living units for nearly three-quarter million residents. According to the American Health Care Association, the number of facilities is in the range of 40,000 to 65,000. The numbers are very difficult to pin down, as a standard definition of an ALF, including services offered by the facility. Such services may include all care management and living services for patients who have disabling chronic conditions or who are simply aged and need help with tasks that are essential to independent living, such as cleaning and cooking.

It is projected by Drummond and Associates of Franklin, Massachusetts, that 1 million ALF living units will be available by the end of 1998, with that number ballooning to 1.4 million by the year 2000. One driver of these estimates is the rapid increase in the aged population. Another driver is the fact that ALFs are cost effective, compared with other care options. The average daily cost of a private room in an ALF is 35% less than that for a private bed in a skilled nursing facility. In fact, the cost of a daily home health nurse visit can average 14% more than an ALF. Therefore, for seniors who are physically able, assisted living can be one of the most cost-effective living options. Revenues for ALFs were pegged at \$15 billion in 1996, with about 85% of all ALFs being run by for-profit companies. It is therefore not surprising that ALFs are the focus of new construction for senior living. Assisted living facilities dominate the new residential construction arena, with freestanding facilities accounting for more than 40% of all new building.

Average medication use of residents in ALFs mirrors that for other seniors, with utilization estimated at six to seven concurrent medications.

It is possible that the rise of the ALF has directly contributed to a decline in nursing home beds, for patients at least 85 years old, from a peak of nearly 700 beds per 1,000 in the mid 1970s to about 350 beds per 1,000 through today. The decline in nursing home beds may also be related to the rise in the ALFs and other subacute facilities.

Figures

Benefits Typically Offered in Assisted Living Facilities

Population Projection for Patients at Least 85 Years of Age

Average Daily Costs of Care Facilities

New Seniors Housing Construction

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AVERAGE DAILY COSTS OF CARE FACILITIES

Assisted Living \$72 per diem, private room

Home Health Nurse \$83 per visit

Skilled Nursing Facility \$111 per diem, private bed (private pay)

Subacute Care \$250 per diem

Acute Care \$521 per diem

POPULATION PROJECTIONS FOR PATIENTS AT LEAST 85 YEARS OF AGE

(IN THOUSANDS)



Skilled Nursing/Assisted Living

Improve Continuity of Care Through Collaboration.

The growth of assisted living provides opportunities for nursing homes.

By Jon M. Thompson, PhD, and LeeAnne Marinaccio, MS

The number of facilities providing residential care and assisted living in the U.S. has increased dramatically in recent years to more than 30,000 in 1994. Despite the national growth of these facilities, nursing home operators know little about them. We surveyed 35 assisted living facilities (ALFs) in three counties of Virginia to learn more about their services and to identify opportunities for nursing homes to collaborate with ALFs.

Why Are NHAs Interested in ALFs?

Some nursing home administrators (NHAs) are concerned about the level of services ALFs provide as well as the threat of competition. (Robert Mollica found in his 1996 survey that state policymakers view assisted living as a substitute for nursing homes.) Other NHAs question the appropriateness and quality of services for patients discharged from nursing homes to these facilities. Finally, many nursing

homes have been the focal point of long-term care in their communities, and administrators want to maintain their leadership position within the changing health care environment. These issues notwithstanding, the growth of assisted living creates opportunities for NHAs to assume increased responsibilities in coordinating the delivery of long-term care services in local communities.

Resident needs and services.

Respondents to our survey identified residents' needs in three functional status areas: Activities of Daily Living (ADLs), continence requirements and levels of ambulation. Eighty-one percent of their residents require monitoring for one or more ADLs; 42% require physical assistance for one or more ADLs. Two-thirds of residents require monitoring for continence; one-fifth of residents require assistance with continence.

Extent of residents' ambulation reflects their degree of independence, and influences their ability to evacuate in an emergency situation. We identified three categories of ambulation: independent (unassisted exit in an emergency), semi-independent (exit with wheelchair, brace or cane in an emergency) and non-ambulatory

(individuals unable to exit in an emergency). Three-fourths of assisted living residents were independent. Semi-ambulatory residents represented 16% of the residents in these facilities, while non-ambulatory individuals constituted 6% of the residents in these facilities. The findings suggest opportunities for nursing homes to serve, in a more appropriate manner, those 22% of assisted living residents who are semi-ambulatory or non-ambulatory.

We also assessed the facilities' care of residents having some form of cognitive impairment: dementia, wandering, Alzheimer's and abusive/aggressive/disruptive conditions. Residents with dementia were generally accepted in 74% of the facilities. Less likely to be accepted—in slightly over half of facilities—were residents who show symptoms of who have been diagnosed with Alzheimer's. Individuals with a tendency to wander often were accepted in fewer than half the ALFs because most cannot keep this type of resident safe. Finally, residents who are aggressive, abusive or disruptive represent a special category of need, yet only 11% of facilities were willing to take them.

Because residents with cognitive

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Skilled Nursing/Assisted Living

impairments have special needs, many ALFs do not represent an acceptable alternative for placement. On the other hand, many nursing homes have developed successful Alzheimer's units or dementia programs that offer an appropriate setting for cognitively impaired residents.

Use of external sources of assistance. Ensuring appropriate service in

ALFs becomes increasingly important as the residents' needs change. When higher skilled care becomes necessary, two-thirds of ALFs acquire assistance from outside organizations, including home health services and physical therapy. Since 95% of the facilities in our sample were freestanding (not part of a diversified retirement community or a nursing home system), perhaps outside assistance can be provided by nursing homes.

Referrals of residents to other sources of care. Residents' requirements will vary with time and may necessitate placement in other, more appropriate settings. What situations necessitate referral to other sources of care? We found that facilities expressed concern when residents' needs were not being met (29%), behavior problems surfaced (14%), residents become non-ambulatory (6%) or a combination of these conditions occurred (20%). Although made for differing reasons, referrals are usually prompted by the resident's needs exceeding the capabilities of the ALF. An unexpected finding was that almost a quarter of facilities indicated that there were no conditions that would necessitate resident referral.

What Are the Opportunities for Nursing Homes?

Nursing homes should position themselves for effective relationship building with freestanding ALFs. Facilities are serving

residents who require assistance with ADLs and who, in many cases, are non-ambulatory. Nursing homes should position themselves as referral providers to care for residents who cannot be adequately served in these less intense settings.

When higher skilled care becomes necessary... perhaps outside assistance can be provided by nursing homes.

Furthermore, because resident needs change over time, facilities are challenged to provide resident services commensurate with need, which typically involves providing higher levels of care. Nursing homes can contract services that are needed by ALFs.

The heterogeneity of residents in ALFs creates challenges for the management of care in these facilities. Referral relationships between ALFs and nursing homes are important for matching the appropriate services to the resident's needs. One role for nursing homes is to assist in the development of guidelines for referral and management of the care of assisted living residents.

Nursing homes should strengthen their services for providing care for individuals with cognitive impairments. Individuals with forms of cognitive impairment are not routinely accepted by many ALFs. This situation creates opportunities for nursing homes to serve residents who cannot be adequately cared for in ALFs. Such referrals may come either after a resident is admitted to an ALF or prior to admission.

Nursing homes should partner with freestanding ALFs in order to offer a continuum of long-term care under managed care contracts. Managed care is advancing into the market for nursing facility services and promises to have a significant impact on service availability. Because of the variation in intensity of residents

served in both ALFs and nursing homes, formal relationships should be developed to provide long-term care services with sufficient breadth to meet the needs of managed care organizations in defined market areas. Links between nursing homes and ALFs will also be viewed positively by hospitals and health care systems that are creating integrated delivery systems.

ALFs represent a major addition to senior living and residential services in the U.S. and create opportunities for traditional nursing homes. We suggest NHAs explore ways to work closely with administrators of ALFs to fill a gap in services. Although our study is limited in scope, the findings point out areas for collaboration as well as areas for additional research in emerging nursing home-assisted living relationships. ♦

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Transforming the Long-term Care System: Policy and Managerial Challenges

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The long-term care system serving persons with disabilities is being rapidly transformed. The population is growing while its composition is changing; the model of care is evolving toward one of independent living; the site of care is moving from institutions to home or community; and the industry is experiencing rapid growth, market structure change, and significant changeover in organizational auspice. A profound cultural shift in attitude toward people with disabilities most recently has been manifested through the enactment and implementation of the Americans with Disabilities Act (ADA). These changes require innovative policies, shaping the transformation in a manner responsive to the needs and preferences of people with disabilities. Simultaneously, these policies must be mindful of resource constraints. In guiding their organizations through this period of transformation, managers also must cast broadly for effective, proactive strategies.

This chapter discusses this transformation in greater detail, along with its implications. We first define long-term care and provide population estimates of people with disabilities. Current long-term care financing is reviewed, as is health and long-term care insurance coverage for people with disabilities. Next is a discussion of system transformation propelled by the changing composition of the disabled population; the independent living movement; the development of a community-based infrastructure for long-term care; technology growth; long-term care industry transfiguration; and efforts to integrate acute and long-term care. The potential impact of the ADA is briefly noted. We conclude with a discussion of both policy issues and managerial challenges posed by this systemic change.

A DIVERSE POPULATION OF PEOPLE WITH DISABILITIES

The need for long-term care arises from serious functional disability associated with limitations in an individual's ability to perform various activities of daily living (eating, walking, bathing) or instrumental activities of daily living (answering the telephone, shopping, managing personal finances). Long-term care, as defined here, includes the provision of support or social services and the provision of assistive devices that help a person with functional limitations to maintain independence and to cope with her or his disabling condition. Long-term care is provided in a variety of institutional, community, and home settings. Both service constellation and setting are somewhat heterogenous across subgroups of people with disabilities.

Estimates of the number of people with disabilities encompass a wide range, dependent somewhat on the data source, definition of disability, method of measurement, perspective of the person offering the definition (i.e., researcher, advocate), and self-perception on the part of people with perceived disabling conditions.¹⁶ Zola⁴⁴ recounts how moving from a longstanding (but arguably stigmatizing) question of "are you physically disabled?" to a series of questions about the presence of chronic conditions, activity limitations, and use of assistive devices increased the number of persons reporting a disability 10-fold in an annual survey of scientists and engineers.

Disabling conditions can affect people at any age. Commonly, discussions of long-term care policy evoke the image of a frail elderly person with deteriorating cognitive abilities in need of nursing care and supervision. Yet a significant population of nonelderly people are in need of long-term care services. In addition to the elderly who are disabled, people with chronic illnesses and disabilities who require long-term care include persons with AIDS; children who are chronically ill, technology-dependent, or otherwise disabled; people with developmental disabilities; and people experiencing serious mental illness or problems with substance abuse.

The prevalence of disability increases with age; whereas 6% of children and youth have a disabling condition, 45% of the elderly who are age 75 or older experience a disabling condition. Multiple disabling conditions rise sharply with age. One in six children with a disabling condition experiences more than one disability, in contrast to one-half of people age 65 or older who experience disability.¹⁵ Of note, age-specific disability rates have been declining for the elderly¹⁹ and increasing for people under age 65.⁹ Among other factors, recent advances in the treatment of AIDS have fueled changes in the composition of the long-term care population. Improved treatments for people infected with HIV have extended their survival time but have left them with substantial long-term care needs. Improved trauma care likewise has resulted in the preservation and extension of life for many people incurring significant injury but left them with substantial disability. Nearly 58% of people with a disability—defined here as a limitation in activity caused by a chronic condition or impairment—are of working age; about 32% are elderly; and approximately 10% are children.³⁵ Despite the size of the younger disabled population, the elderly who are disabled are much more likely to need long-term care, accounting for approximately 60% of people with long-term care needs.

Although long-term care populations have in common serious functional disability, specific service needs are somewhat heterogeneous. For example, people with developmental disabilities often require income maintenance, habilitation (e.g., training in self-care), education and vocational training—services distinct from the more maintenance-oriented needs of the elderly. Younger people with AIDS often need child care, treatment for substance abuse, and other support needs not required by the frail elderly. Although they often share a need for home care, people with AIDS often may present more medically complex problems and require greater intensity of care than elderly persons in need of long-term care.⁴⁰

NATIONAL EXPENDITURES

In 1993, 11% (\$99.1 billion) of all national personal health expenditures were spent on long-term care services—nursing home, home health, and community-based services provided

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under Medicaid. Of this, 36% (\$35.4 billion) came from personal resources, 46% (\$45.2 billion) from Medicaid, and 17% (\$17.0 billion) from Medicare.⁶ An additional \$1 billion of nursing home care was provided through other public dollars. These figures suggest that long-term care services are predominantly funded by public dollars. Most expenditures go to institutional care: more than twice as much was spent on nursing home care as on home health services (\$70 billion vs. \$25 billion). Expenditures on nursing home and home health have increased substantially. In 1980, approximately \$20 billion was spent on nursing home care, compared with \$70 billion in 1993. Home health care expenditures have risen even more dramatically, from \$2 billion in 1980 to \$25 billion in 1993. Overall, national expenditures for home health care grew faster than any other category of personal health care in 4 of the past 5 years.

Discussions of the shares of public and private spending on long-term care are complicated by the fact that there is no straightforward way of isolating expenditures on long-term care services. For example, although it is accepted practice to count all Medicaid nursing home and home-based care as long-term care, some portion of these expenditures are for postacute care. Similarly, some spending on what are typically viewed as acute care services in fact meet a segment of long-term care needs—mental-health-related physician services, for example. Similar phenomena characterize Medicare spending as well as private spending.

Another complication is that some of the increase in long-term care expenditures may be an artifact of the U.S. system of national health accounts. Expenditure trends reflect only the financial value of market transactions, excluding the value of informal, unpaid care given by family members and friends. Some have suggested that informal care may have decreased somewhat over the past decade. Thus, it may be that total societal resources devoted to long-term care may not have increased as rapidly as the measurable dollars indicate. Nevertheless, the total burden of long-term care, whether provided formally or informally, is certain to increase in the future.

Medicare Expenditures

During the past decade, Medicare spending on skilled nursing and home health care expenditures dramatically increased, as has the number of people served. In 1980, spending on both skilled nursing and home health accounted for just over 3% of total Medicare benefit payments. By 1992, this increased to 8%, and by 1995 skilled nursing and home health care dollars are projected to exceed 11% of total expenditures.⁶

Between 1980 and 1990, Medicare payments for skilled nursing care sharply increased, growing from \$0.4 billion in 1980 to \$6.1 billion in 1993. More recently, Medicare's share of public spending for nursing home care rose significantly from 4.1% in 1988 to 14% in 1993. In 1993, Medicare expenditures for home health care services reached \$10.9 billion (including spending for both facility- and non-facility-based home health agencies), up from \$8 billion in 1980.

Medicaid Expenditures

Medicaid accounted for 90% of public spending for nursing home care from 1972 through 1988, dropping to 82.6% in 1993. The drop in Medicaid's share was offset by a corresponding increase in Medicare's share. In 1980, federal Medicaid spending on nursing home care was \$6.1 billion, and in 1993 that figure had risen to \$36.0 billion. Between 1980 and 1993, Medicaid spending on home health care services increased more than 20-fold from \$0.2 billion in 1980 to \$4.5 billion in 1993. In 1993, Medicaid spending on other community-based services such as personal care and 1915(c) waivers totaled \$4.7 billion.

Private Expenditures

Private spending on long-term care services also has increased substantially over the past decade. Private insurance paid \$0.2 billion for nursing home services and \$0.3 billion for home health services in 1980. These expenditures rose to \$1.7 billion for nursing home care and \$2.5 billion for home health services in 1993. Out-of-pocket expenditures have experienced more

noticeable increase. In 1980, out-of-pocket expenditures for nursing home care were \$7.8 billion but nearly tripled to \$23 billion in 1993. Home health care out-of-pocket expenditures increased from \$3 billion in 1980 to \$4.3 billion in 1993.

SOURCES OF PRIVATE AND PUBLIC INSURANCE BY SUBGROUP

People with disabilities are disproportionately poor. Thirty eight percent of those under 65 years of age and 24% of those who are 65 years of age or over live below the poverty level. In contrast, 16% of those under 65 years of age and 10% of those 65 years of age or older without disabilities live under the federal poverty level.³⁶ Hence, public funding of services—Medicare and Medicaid—is of even greater concern to the disabled relative to the general population.

Our focus is on the long-term care needs of people with disabilities. Yet these needs cannot be divorced from access to and use of acute care services. Fasser et al.¹⁰ note the general agreement that many people with disabilities have a "narrow margin of health," i.e., increasing susceptibility to health problems. For example, a lack of tactile sensitivity, poor circulation, and diminished mobility may result in dermatologic problems, whereas the loss of normal motor or sensory control of the bladder may result in urinary tract problems.² With these concerns in mind, many somewhat routine health problems experienced by people with disabilities are preventable if adequate, timely health care is made available. Fasser and colleagues identify three key features of such health care: (1) prevention services; (2) early intervention by physicians and other health care practitioners who are knowledgeable about disability-related health problems; and (3) support systems required for early detection of potential problems by the person with a disability, that person's personal care attendant, or a health care practitioner.

Long-term care is provided mostly on an informal (unpaid) basis by family and friends. Most persons with long-term care needs are living in the community—only 18% receive institutional care.³⁶ Among people with functional disabilities who live in the community, roughly 90% receive some informal help, whereas 67% depend solely on help from family and friends, which often is provided with significant emotional and financial cost.

The following discussion describes public and private coverage for both acute and long-term care services. The previously cited national trends mask important differences by subgroups of people with disabilities with respect to public or private insurance coverage, both for acute and long-term care needs.

Elderly People

Among all groups in the U.S. population, the elderly are the least likely to be without health insurance. Over 97% of persons age 65 or older are eligible for Medicare. Medicare provides a basic infrastructure of health care services for the elderly with long-term care needs. At the same time, Medicare is designed to be an acute-care benefit and does not cover the substantial costs of long-term nursing home care. Of note, despite its acute orientation, Medicare provides increasing amounts of long-term care-like services, primarily through the rapidly growing home health benefit.³⁹

In addition to Medicare services, low-income elderly persons may qualify for Medicaid, which provides more substantial long-term care benefits, depending on the person's financial status and level of functioning. Principally, Medicaid funds extended nonskilled nursing home care as well as a variety of home and community-based services. Most states have a medically needy program whereby elderly persons may become eligible for Medicaid if their medical expenses cause them to spend down to Medicaid eligibility levels. Just over nine percent of the elderly are eligible for both Medicare and Medicaid.

Although it is growing, purchase of private long-term care insurance by the elderly continues to be quite limited. Despite recent improvements in their financial status, private long-term care insurance is costly for many, with the annual premium for a 65-year-old averaging about \$2,525 in 1991 and rising rapidly to \$7,675 for a 79-year-old. Surveys conducted by the

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Health Insurance Association of America found that the number of policies sold increased from 815,000 in 1987 to more than 2.9 million in 1992. These figures should be interpreted with caution since lapses and deaths cause the number of policies in effect to be substantially less than the number of policies sold (probably on the order of 2 million).⁴²

Despite the benefits available under Medicare, Medicaid, and private insurance, the elderly still endure significant financial hardship because of rising out-of-pocket costs for long-term care. In 1993, about one-half of nursing home expenditures and about one-fourth of home health care expenses were paid out-of-pocket by elderly Americans.⁴³ With the average cost of a nursing home stay exceeding \$37,000 in 1993, a stay of even moderate length can have substantially devastating consequences for elderly people and their families.

Children

Unlike the elderly, a significant number of children are without health insurance. Data from the 1989 National Health Insurance Survey reveal that of the estimated 35 million people without health insurance in the U.S., 10 million are under age 18. Furthermore, children with disabilities are less likely than children without disabilities to have private insurance (57.5% vs. 70.2%, respectively) and more likely to rely on public programs. Fully one-fourth (25.9%) of children with disabilities are covered under public insurance in contrast to 13.4% of children without disabilities.¹⁷ Access to private insurance, moreover, may not provide adequate coverage of health care needs for children with disabilities.

In regard to public payment sources, a child who is disabled and meets income and disability criteria for Supplemental Security Income (SSI) is eligible for Medicaid in most states. After the 1990 Supreme Court decision in *Sullivan vs. Zebley*, the Social Security Administration developed new regulations to make SSI eligibility determinations more appropriate for children with disabilities. Preliminary estimates indicate that the number of SSI-eligible children has increased from 275,000 in 1989 to 900,000 in 1994³⁴ and is projected to increase to 1.4 million in the year 2000.

Working-Age Disabled

Occupying a particularly precarious position are people with disabilities of working age. The working-age disabled are significantly more likely to be uninsured than those without disabilities (17.8% vs. 16.6%) and are significantly less likely to have private coverage alone (54.7% vs. 77.7%). Over one-fourth (26.9%) of the working-age disabled rely on public insurance alone and are five times as likely as the working-age population without disabilities to be covered by public insurance.¹⁷ Many with private insurance are significantly underinsured because of restrictions on coverage such as preexisting condition exclusions. Furthermore, many often find that the services they most need, such as personal assistance or durable medical equipment, are not covered.⁹ Although qualifying for SSI gives one Medicaid eligibility and receipt of Social Security Disability Income (SSDI) payments provides Medicare eligibility, the two-year waiting period for Medicare eligibility leaves many working-age disabled people without insurance at a critical point in their disability trajectory. Consequently, people with disabilities are more likely than people without disabilities to be uninsured or underinsured or to rely on public health insurance. Although low-income individuals who are disabled have Medicaid eligibility, existing eligibility criteria often may deter people with potentially costly medical needs from seeking work for fear of losing Medicaid eligibility.

Access for some groups may have improved. For example, there has been a dramatic increase in the number of people with mental disorders on the disability rolls. In 1985 the Social Security Administration established separate criteria for eligibility for SSI and SSDI applicants with severe mental illness. The revised listing of mental disorders was instrumental in the dramatic increase in the number of people with mental disorders on the disability rolls. The unduplicated number of SSDI and SSI beneficiaries with a primary mental health diagnosis as the basis for eligibility grew from 739,000 in 1986 to 1,154,000 in 1991.

ISSUES FUELING SYSTEM CHANGE

Changing Composition of the Population

Growth in the number of beneficiaries with disabilities, coupled with a change in the composition of this population, will profoundly affect the Medicare and Medicaid programs over the next several years. In addition to the growing number of elderly most likely to experience functional disability, the number of nonelderly disabled Medicare beneficiaries is growing rapidly. From 1983 to 1992, the number of Medicare disabled increased 18% to 3.2 million and is projected to almost double from 1983 to 2000 to 5.3 million.⁴

The Medicare disabled are younger, more likely to be male, more likely to be of an ethnic or racial minority, and poorer than aged Medicare beneficiaries. About 25% experience serious mental health problems, and another 20% are disabled because of musculoskeletal disorders. Only 5.4% are disabled because of a developmental disability.⁵ A comparison of the functional status of the disabled with aged Medicare beneficiaries suggests that Medicare's disabled beneficiaries are more likely to report some limitations in activities of daily living such as eating, bathing, dressing, and toileting. Furthermore, those who are disabled are more likely than the aged to report their health status as fair or poor.¹³

The Medicaid program also has been significantly affected by the growth in the number of low-income disabled people. Between 1985 and 1995, the number of low-income disabled people has grown from 6.1 million to an estimated 10.4 million, with the rate of growth higher for nonelderly disabled people (103%) than for elderly disabled patients (39%). Within the Medicaid program, serious mental illness and developmental disabilities are important sources of disability for both adults and children. In 1994, 33.5% of adults and 22.1% of children enrolled in Medicaid experienced a disability due to mental illness. Almost one-fourth (24.1%) of adults and 39.1% of children were functionally impaired because of a developmental disability.³⁵

The growth and change in composition of the population of people with disabilities over time is likely to affect the types and intensity of services used within Medicare and Medicaid. In particular, Medicare, long an acute health care-oriented program, will need to recognize the long-term care needs of its disabled beneficiaries as well as the relationship between acute and long-term care for these beneficiaries.

The Independent Living Model of Care

For a number of years now, momentum has been building within the disability communities to insist on the right of people with disabilities to live independently in the community. This momentum has garnered support for consumer-directed care models as well as an insistence on access to the types of services that are necessary for an independent living model to work.

Under this model, the person with a disability is an active person who recruits, selects, manages, and directs his or her provider of services, who is known as a personal assistant. The person with a disability becomes an active consumer to whom the personal assistance provider is accountable. Often the personal assistance provider is not trained and not supervised by a nurse or other trained professional. This is in clear contrast to the medical model, which has long undergirded the provision of long term care—a model in which the person with a disability is a passive recipient of care, and the service provider, a professional or paraprofessional under supervision, provides care and is accountable to an agency.³

Access to personal assistance services is critical in the independent living model. Services provided by a personal assistance provider include assistance in activities of daily living (e.g., bathing), instrumental activities of daily living (e.g., meal preparation or laundry), reader services for those who are blind, and interpreter services for those who are deaf.¹⁸

Some states are beginning to adopt an independent living model in their long-term care programs. For example, Massachusetts, Maine, California, and Pennsylvania have committed

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state resources to finance personal assistance services or have incorporated concepts derived from an independent living model in their interpretation of regulations for community-based long-term care, such as Medicaid 1915(c) waivers.³

Emerging Community-Based Long-Term Care System

Somewhat in concert with the movement toward an independent living model has been the evolution of long-term care systems from largely institutional to home- and community-based settings. This evolution is most clearly seen in Medicaid-funded long-term care. Medicaid funds a variety of community-based long-term care services, including home health, personal care, and various services under the auspices of the 1915(c) waiver program. In 1982, the year in which 1915(c) waivers were authorized by Congress, approximately 2% of Medicaid dollars funded long-term care services in homes and communities. By 1995, almost 25% of Medicaid funding covered community-based long-term care.¹²

Care for people with developmental disabilities represents the most striking case of this movement from institutions into the community. The population living in large state intensive care facilities for mental retardation (ICF/MR) has declined markedly since the mid 1960s. Although many people with mental retardation and developmental disabilities continue to live in residential facilities (50% of those receiving home- and community-based waiver services in 1994, for example, lived in residential facilities), the residential facilities in which they now live are much smaller than they once were. And an increasing number of people are living in their own homes.²⁷ This significant movement from the institution to the community has been made possible, in part, by programmatic responses—namely Medicaid home- and community-based waivers—fired by changing expectations about the kind of care that persons with mental retardation and developmental disabilities should receive.

Indeed, what constitutes a person's home or an institution is becoming increasingly blurred by a convergence of recent trends. Personal assistance services increasingly are provided to people with disabilities who are not home-bound according to Medicare and Medicaid coverage criteria. These services provide assistance to people with functional impairments well beyond their home into the community where people who are disabled pursue work and social opportunities. In addition, home care can now be provided in homes that are in actuality apartments within assisted living facilities, blurring the line between home and institution.¹⁵ This loss of demarcation, in concert with the movement toward independent living and client choice, may fundamentally alter the nature of the long-term care system.

State flexibility in the Medicaid program results in variation in the availability of long-term care services—home health, optional services such as personal care, and access to 1915(c) waiver services. In 1993, Medicaid per-capita long-term care expenditures averaged \$1,310 across the states. This overall average masks important differences. California spent an average of \$475 per capita, whereas Connecticut spent an average of \$3,421 per capita in 1993. Within this per-capita expenditure variation resides significant variation in the mix of institutional and community-based expenditures. An array of home- and community-based services accounted for 47% of Oregon's long-term care expenditures and skilled nursing facility care accounted for 35.1% in 1993, whereas in California, noninstitutional services accounted for only 2.6% of the \$2.3 billion spent on long-term care services in 1993.²⁵

Technology

As with personal assistance services, people with disabilities and their advocates have focused attention on assistive technology, viewing adequate access as the key to independent living. Assistive technology includes such items as communicative aids, wheelchairs, prosthetic and orthotic devices, computer-assisted environmental control units, and other items used by people with disabilities to compensate for functional loss and to prevent progression of illness.

Within the Medicare program, assistive technology is a term with no specific meaning. Categories of Medicare services into which assistive technology generally fits include durable

medical equipment (DME) and prosthetic devices. Several concepts in Medicare coverage criteria create significant barriers—concepts of “home” and “homebound,” “durable,” and “of a medical nature or use.” For example, DME is intended for use in one’s home; yet equipment, such as a wheelchair, designed for the home will clearly not support the integration of a person with a disability in the community—a setting requiring somewhat more sophisticated equipment to enhance mobility.

As a second example, traditionally the Medicare and Medicaid programs have required that DME serve a medical purpose (necessary to treat a beneficiary’s illness or injury) and that its cost be reasonable “given the expected benefit.” Even within this traditional framework, there are a number of ambiguities. Concerns have been raised that the government is making unnecessary payments for equipment that is not medically necessary or that is more sophisticated than is needed. There is already a sense that Medicare and Medicaid coverage criteria are vague and subjective, leading to an expressed desire on the part of carriers as well as other experts that more specific criteria be developed.³⁸

Professional consensus around appropriate use of assistive technology is lacking. Moreover, primary care physicians are often ill-equipped to deal with these determinations. It is difficult to measure the outcomes—the benefits to health and function—and the personal assessment of the user of the technology must generally be accepted.

Industry Transformation

Recent years have witnessed a transformation of the long-term care industry. The sheer increase in the number of long-term care providers commands attention, as does the large-scale changeover from a system composed of public and non-profit providers to for-profit providers. As with the larger health care system in the U.S., significant system structural change through organizational actions, such as vertical integration of long-term care providers with hospitals and other system providers, is evident.

Between 1991 and 1994, total industry growth across a range of long-term care provider types—hospice, home health, outpatient physical therapy, comprehensive outpatient rehabilitation, ICF/MR, and nursing home—ranged from 4–48%. Although the nursing home industry, at a 4% growth rate, represents a somewhat mature, stable industry, the growth in home health and hospice providers is particularly striking, and there is little to suggest an attenuation of this rate of growth in the near future.¹⁴

With the exception of the nursing home industry, an industry composed largely of for-profit providers, the rate of growth of for-profit providers has been the greatest, compared with nonprofit and public or government providers. For-profit provider growth, over the 4-year period, ranged from 23–164%.¹⁴ Although it is probably too early to gauge the impact of this industry transformation, emerging research suggests a need to attend to the change. An analysis of the impact of organizational form in the home health industry suggested that beneficiaries receiving care from a for-profit home health agency received 21 more visits than beneficiaries receiving care from nonprofit agencies, controlling for differences in health and functional status of the beneficiary as well as age, sex, and living situation.²⁰ A clearer understanding of these service pattern differences and their impact on quality of care and outcomes across the long-term care industry is critical.

Market structure changes also affect the long-term care industry. To illustrate, hospitals have been acting strategically through vertical integration, particularly into the postacute-care provider sector—nursing home, home health, and comprehensive outpatient rehabilitation facility.²⁸ Between 1991 and 1994, the number of hospitals with their own home health agency increased from approximately 25% to 33%, about a 30% increase over the 4-year period. The decision to integrate vertically relates to a variety of demand factors in the market area as well as factors such as bargaining power of the hospital, all of which shape the structure of strategic behavior.²² As with the transformation to a for-profit industry, the impact of such market structure changes requires an understanding of their impact on patient choice of

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provider, quality of care, and outcomes. For example, hospital integration into postacute care may limit choice to facilities affiliated with the hospital, despite patient preferences for specific types of care.

Integration of Acute and Long-Term Care

There is increasing interest in the development of managed care models of service delivery that integrate acute and long-term care services. Persons with disabilities tend to have higher acute care costs than persons without disabilities and are much higher users of institutional services to meet basic acute and long-term care needs. These models strive to prevent functional decline that can result from unmet needs and inappropriate care and work to produce acute care savings by substituting lower-cost outpatient and home-based services for more costly inpatient services when appropriate.

To date, the operational programs that fully or partially integrate acute and long-term care services are limited. Traditionally managed care systems such as health maintenance organizations (HMOs) have generally not enrolled persons with disabilities, nor have they generally expanded their services to include long-term care. The record regarding how well managed care providers, such as HMOs, provide care to persons with disabilities is mixed.^{23,26,29,31} Furthermore, some long-term care advocates worry that the consolidation with acute care will result in undesirable medicalization of long-term care, accompanied by a loss of consumer autonomy and higher costs.¹

Despite the challenges in developing integrated systems, providers and states are increasingly interested in experimenting with such programs. The ten-site Program of All-inclusive Care for the Elderly (PACE) demonstration and the three-site Social Health Maintenance Organization (Social HMO) project exemplify provider-sponsored integrated systems. The PACE program is seeking federal legislation for permanent Medicare status, and the Social HMO model of care is under refinement at six additional sites. Additionally, several state-sponsored integrated care projects are in various stages of development or implementation. State efforts focus on various subgroups of people with disabilities, including children (District of Columbia); people who are dually entitled (Colorado, Connecticut, Maine, Minnesota, Massachusetts, New Hampshire, Rhode Island, and Vermont); people with developmental disabilities (Rhode Island); and the nonelderly physically disabled (Wisconsin).

Americans with Disabilities Act (ADA)

The ADA, passed in 1990, symbolizes a profound cultural shift in society's attitudes toward people with disabilities as well as a shift in the attitudes of people with disabilities toward themselves. The ADA was devised in response to what members of both the U.S. Senate and House of Representatives identified as a compelling need to provide a clear and comprehensive national mandate for the elimination of discrimination against people with disabilities and for the integration of people with disabilities into the economic and social mainstream of American life.³⁰ Such a broad mandate suggests some obligations on the part of the health care system—especially the publicly financed insurance system through which an increasing proportion of people with disabilities receive access to care.⁷

Yet others argue that the ADA offers conflicting messages about insurance coverage for people with disabilities.¹ Thus, the impact of the ADA on transforming the present long-term care system into one more responsive to the needs and preferences of people with disabilities remains unclear. For example, lawsuits recently filed by persons with disabilities have argued that the failure to provide appropriate community-based services (as a substitute for institutional care) is a violation of their rights under ADA. At least one court has found, however, that states have the right to choose how they will provide for people with disabilities (in institutional or community-based and home settings) as long as services provided to people without disabilities are available on an equal basis to people with disabilities.³⁷

A RESEARCH AND POLICY AGENDA

Enhancing Access

A significant number of non-working people who are disabled lack health insurance, as do children with disabilities. People with disabilities who are insured rely heavily on public funding through Medicaid and Medicare. As the population of people with disabilities continues to grow and change, there will be increasing pressure to improve coverage, both through private and public sectors.

In the private sector, improving access for people with disabilities is intimately related to the overall problem of the uninsured. Several remedies have been considered by Congress—small market insurance reforms, employer-mandated provision of health insurance, Medicaid expansions, and miscellaneous solutions such as continuation of bad debt and charity pools, to name a few. But the lack of consensus regarding policy remedies, alongside the absence of viable political structures to build such a consensus, continue to impede significant reform on the national front.⁵ To the extent that people with disabilities have faced discrimination in hiring decisions and subsequent health insurance coverage attained through employment, passage of the ADA, policy statements issued by implementing agencies such as the Equal Employment Opportunity Commission, and legal clarification may begin to address some access concerns in the private sector.

There is even less consensus about how to meet the growing need for long-term care for people with disabilities. Access to long-term care services for many people with disabilities depends on criteria used to determine eligibility for public income maintenance programs. Within the realm of Medicare and Medicaid, several options to improve access exist, including removing or modifying the 2-year waiting period for Medicare; expanding eligibility for government-sponsored programs; enhancing opportunities for people who are disabled to "buy-in" to Medicaid or Medicare; and increasing flexibility within the Medicare program to meet more appropriately the long-term care needs of enrollees with disabilities. Again, discussion focuses on the issue of latent demand—what would be the impact of increased insurance coverage on service utilization and the ability of public sources to pay. Research and demonstrations that test some alternatives, such as enhanced Medicare buy-ins for SSDI-disabled people who are uninsured during the 2-year waiting period, may assist in determining the impact of such changes on program expenditures and beneficiaries' access to services.

One area that may merit special attention is how program eligibility criteria may interact with incentives for people who are disabled to seek employment. Generally, public programs restrict access to Medicare and Medicaid services for people who return to work. Such policies may constrain the growth of program expenditures, but they may leave a significant number of persons with disabilities without health insurance or serve as a deterrent to returning to work. As with efforts to improve access to health insurance, research and demonstrations that test the effect of policies such as a Medicaid buy-in for people with disabilities who return to work—particularly those who appear constrained by the income caps established under 1619(b) provisions—are key to informing policy.

It is important to enhance availability of services that are fundamental to meeting the long-term care needs of people with disabilities but that presently are either not provided or restricted through features such as medical necessity criteria. Personal assistance services frequently are not covered in private insurance and are not uniformly available through Medicaid or other public sources. Access to appropriate mental health care services are often lacking or restricted in both private and public insurance plans. Other examples are available.

Remedies may be private or public and depend somewhat on employment status. In addition, some services, such as personal assistance services, may fit less comfortably in an insurance structure. For a working-aged person who is disabled and employed, support for personal assistance services could be derived from tax credits, tax deductions, or sliding fee scales.⁹

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Public remedies would attend to the role of public health insurance programs in providing these services (relative to other public sources such as Title XX for personal assistance services, for example) as well as payment options such as prospective budgets and vouchers to address fiscal concerns.

Building the Long-Term Care System Infrastructure

People who are disabled, their families, and their advocates demonstrate strong preferences for accessing long-term care services in their home and surrounding community. As previously noted, these preferences are further fueled by cultural shifts and legal remedies that view integration of people with disabilities into the economic and social mainstream as critical. Given countervailing concerns with the costs of care, it is important to note that care provided in one's home or community tends to cost no more, and possibly less, than institutional care for most people who are disabled.²⁴

Significant disparities exist across states in the availability of home- and community-based care relative to institutional care. Some preliminary work suggests that policy instruments such as matching funds, certificates of need, and bed moratoria may be used by the federal and state governments to foster investment in creation of a community-based infrastructure.²⁵

Many people in need of long-term care, when faced with a decision between institutional care and no formal care, choose the latter, whereas, faced with the decision between home care and no formal care, choose home care.⁴⁰ A continuing question in the movement toward community-based care is the number of people who will seek formal long-term care services, given availability of community-based settings. Although one may view this as a significant impediment (can available resources cover induced demand?), others suggest that payment strategies and other allocation mechanisms can balance demand with available resources. For example, several states have developed effective mechanisms to allocate community-based services under their 1915(c) waiver programs.³³ Future studies might explore various ways of paying for community-based care that would not increase costs unduly.

Other building blocks of the long-term care infrastructure include mechanisms for care coordination, quality assurance systems, information systems, and payment methodologies. For example, significant progress has been made over the past several years in outcome-based quality assurance. Systems have been developed and are being tested for Medicare skilled nursing and home health care. Furthermore, outcome-based, client-directed quality assurance is being tested for persons with developmental disabilities in Medicaid demonstrations, and the best practices are being distilled and shared by states who are leaders in community-based long-term care. This work is driving policy changes in how quality is assessed and from whose perspective in the context of Medicare and Medicaid long-term care.

Most payment reform within public long-term care has focused on either benefits (such as prospective payment for skilled nursing care and home health care) or has been encompassed in models of capitation. Supporting continuing evolution of long-term care toward a model focused around and directed as much as possible by the consumer and/or informal support system requires attention to payment strategies that support the needed flexibility yet can respond to fiscal constraints. Research and demonstrations focused on prospective budgets or allowances, vouchers for certain benefits within an overall capitation, disability allowances, and other payment reforms are essential to this development.

Shaping Industry Transformation

Clearly, policies that can appropriately shape industry growth and transformation must rest on knowledge of the effects on access, quality, and costs of long-term care for people with disabilities. Research must assess more systematically the effects of industry growth and transformation, including analyses of specific policy variables designed to align industry change with long-term care system goals.

MANAGERIAL CHALLENGES

Managing innovation and change in a period of system transformation is perhaps the signal challenge facing managers in the long-term care industry. Understanding the types of change the organization confronts, as well as the processes for managing various types of change, is key. Typically, health care organizations may experience four types of change—technical; product or service; administrative, structural or strategy; and human resources.⁸ These types of change may not be mutually exclusive, nor are they strategies for effectively managing change.³²

For example, the decision of a hospital to vertically integrate into postacute care constitutes a change in organizational strategy while simultaneously offering a new service. In turn, the offering of a new product may entail the need to attend to human resources so as to minimize the potential negative influences on existing staff. Managers must be cognizant of the processes to effect each type of change, as well as the interplay of these processes throughout the period of transformation.

The blurring line between home and institution requires managers of traditional long-term care organizations such as nursing facilities to rethink the nature of their organization—client to staff relationships, physical structure of the facility, measure(s) of quality of care, and organizational effectiveness. A different dynamic is introduced by a nursing home population that arguably is now sicker, experiences a shorter stay, and may require rapid discharge to other health facilities. This dynamic requires managers to change care management within the nursing home (for example, through use of teams composed of geriatric nurse practitioners and a geriatrician) as well as to integrate the nursing home more closely with other providers in the care network.¹⁵

Workforce issues will continue to confront the long-term care industry. For example, the emergence of personal assistance services raises significant challenges—redefining the role of the provider to the client; reconceptualizing the role of agencies in personal assistance services provision; addressing provider supply, training, and compensation concerns, to cite a few. Workforce supply, training, and composition issues extend well beyond the boundaries of personal assistance services in long-term care. Fostering an effective, stable paraprofessional workforce is a longstanding issue, for example, in the provision of home health.

In a significant way, industry structure and workforce issues are related. For example, Gould, Haslanger and Vladeck¹¹ have argued that the home health care industry should be reconstituted to support larger, more complex agencies. Such agencies may be better equipped to provide the full range of services required by the increasingly diverse home health population. These agencies would have increased capacity to manage more fully activities such as multidisciplinary care coordination, employee training and supervision, and quality assurance. Additionally, these agencies would be able to attract and retain a more qualified work force. Increased agency size, combined with a more diverse patient population with multiple and complex needs, creates an organizational environment in which the provision of ongoing professional training and the development of more career opportunities are likely to emerge.

People with disabilities require a mix of acute and long-term care services that respond to medical, functional, and social needs. The utility of interdisciplinary teams is increasingly recognized as a central ingredient in managing the diverse and complex needs of many people with disabilities. The composition and role of such teams will differ somewhat, depending on the specific population of the disabled and their service needs. Various factors—composition and size of the team, personality of team members, effectiveness of the team leader, and communication and decision-making procedures—can affect the effectiveness of teams in determining the need for and coordinating the diverse needs of people with disabilities. Models of interdisciplinary teamwork can be found in hospice care, the rural swing-bed program, various geriatric evaluation and management configurations, and innovative capitation demonstrations such as the Program of All-inclusive Care for the Elderly. Yet research is just beginning to attend

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to actual team skills and processes that lend themselves to more or less effective team work in long-term care.²¹

CONCLUSION

The population of people with disabilities is growing, and becoming increasingly diverse. People with disabilities, as well as their families and advocates, are challenging the medical model of long-term care, seeking transition to a model that is consumer-centered and consumer-directed—a model that facilitates autonomy, independence, and community integration. Legal remedies, such as the ADA, and programmatic shifts in Medicaid and Medicare support this transformation.

Yet significant impediments remain—confronting the issue of access to private and/or public financing for acute and long-term care services; building community systems of care in the many localities where institutional care continues to dominate long-term care; aligning the significant changes in the long-term care industry with the goals of people with disabilities and their families; and fostering an effective, stable paraprofessional workforce to provide long-term care. Although modest health insurance market reform is under consideration by Congress, any gains from private sector insurance reform must be carefully measured against efforts to restructure and restrain Medicare and Medicaid.

Meeting these challenges, both policy and managerial, will continue to demand creativity, skill, and perseverance by the community of people who, in various roles, attend to the long-term care needs of people with disabilities.

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MANAGED CARE AND ASSISTED LIVING: TRENDS AND FUTURE PROSPECTS

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ABSTRACT

With its emergence as a new, residential long-term care option, more than half of the states have established policy on assisted living. In 1996, over 30 states had created a state licensure category or passed legislation authorizing development of regulations. Known primarily as a resource for wealthy elders needing assistance with activities of daily living and health care needs, assisted living is increasingly being covered as a service under state Medicaid programs. Assisted living is widely seen as a resource for managed care organizations enrolling Medicare beneficiaries. Flexible capitation payments and incentives to substitute services create opportunities for assisted living facilities and HMOs to form partnerships. Enrollment of beneficiaries in Medicare HMOs has reached 4.5 million and is growing over 30% a year.

In addition, state Medicaid agencies are developing programs to enroll elders, most of whom are also Medicare beneficiaries, in managed care programs that include long-term care. The move toward managed care and the increasing interest in integrating acute and long-term care for dual eligibles signals a growing role for assisted living facilities as a major resource for elders who need a supportive and service-rich residential living environment.

INTRODUCTION

Two parallel trends potentially signal a new dynamic in long-term care--the growing enrollment of Medicare beneficiaries in managed care plans and the expansion of assisted living as an alternative to nursing homes. Linkages have also been supported by the movement of state Medicaid programs toward capitated long-term care programs. In December 1996, 4.1 million beneficiaries were enrolled in 21 managed care plans with Medicare risk contracts, a 33% increase

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over December 1995, compared to 1.4 million who had joined HMOs in 1991.

Despite the rapid growth, enrollment is concentrated. Ten states account for 75% of the enrollees--California, Florida, Pennsylvania, New York, Arizona, Texas, Massachusetts, Oregon, Washington, and Illinois. There was no enrollment in 13 states as of April 1997. States with the highest percentage of enrollment of Medicare beneficiaries are: California (35%), Arizona (34%), Oregon (27%), Colorado (22%), Florida (21%), and Nevada 20% (Health Care Financing Administration, 1997).

The number of assisted living facilities is difficult to measure because of confusion about the definition and variations among state licensing guidelines. State regulation of assisted living has intensified. In 1996, thirty-one states had established policies concerning assisted living (Mollica and Snow, 1996). Fifteen states have existing licensure regulations for assisted living facilities and regulations are being developed by an additional nine states. Twenty-two states reimburse or plan to reimburse assisted living as a Medicaid service, including states that do not have a licensure category for assisted living. Six states provide Medicaid payments for services in board and care settings and thirteen states had created a task force or a process within a state agency to make recommendations for the development of assisted living rules.

Further arrangements between assisted living and managed care plans will differ depending on the source of reimbursement--Medicare or Medicaid. While Medicare HMO enrollment is growing, Medicare does not cover long-term care and the rationale for contracting with assisted living facilities is less apparent. On the other hand, state Medicaid directors are exploring contracting with HMOs to deliver long-term care services. This article explores the assisted living implications of managed care in both the Medicare and Medicaid programs and the types of arrangement that might be developed.

MANAGED CARE AND ASSISTED LIVING

Managed care networks form to manage the delivery and financing of services. Although an integrated network may not receive a capitation payment, vertical integration facilities coordinate services across providers regardless of financing. Networks serving elders may include assisted living and home care providers. Networks

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receiving capitation payments that are responsible for providing and managing a specific list of covered services have financial incentives to provide the most appropriate and cost-effective care. The role of assisted living varies with the reason for forming an integrated network and the availability of capitation payments.

There are three potential relationships between assisted living facilities and health maintenance organizations (HMOs). First, facilities can be part of an HMO network that manages the delivery of services. Second, HMOs may consider reimbursing for services in assisted living facilities as a substitution for Medicare covered services. Third, HMOs may reimburse assisted living as a service covered by Medicaid managed care programs that include long-term care services.

Many organizations are forming vertically integrated networks in order to deliver care for older people more efficiently and to improve coordination among providers of care. Assisted living facilities which also provide other services may have more leverage with HMOs. As health care providers form horizontally and vertically integrated networks, assisted living facilities have the same opportunities. Assisted living companies may view themselves as a potential hub of residential and health services, offering residents and neighbors a range of services. Assisted living settings can be viewed as a center for accessing a range of health and supportive services for both residents and members of the surrounding community. Chronic disease management programs can also be developed by facilities which would enable an HMO to deliver services in a manner that requires far more coordination in other residential settings and is more cost effective than in an institutional setting.

To deliver more medical, post-acute care, assisted living facilities must have access to necessary professionals, provide competitive pricing for custodial care and services, possess the clinical capability to manage services, offer short-term stays, and possess the system capacity to measure and report on HMO quality outcomes (Alborn, 1996). Over time, Medicare HMOs will be interested in developing options for enrollees to avoid the traditional pattern of moving beneficiaries from a hospital to a rehabilitation facility and to a nursing home. Assisted living offers HMOs an opportunity to coordinate services in a residential setting and avoid the rehabilitative stay and nursing home placement. Services in the assisted living setting may be provided by other contractors and coordinated by the HMO or by the assisted living facility itself. Developing residential

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options may avoid the tendency for elders to become dependent and isolated in other long-term care settings and maintain family involvement that tends to diminish.

The key to developing ties between managed care and assisted living is the perceived value of assisted living by the HMO. As long as the beneficiary needs a skilled level of care, HMOs should be willing to pay a negotiated per diem with the facility covering room and board and whatever services are provided by the facility. When the beneficiary recovers and needs custodial services, the HMO most likely will no longer pay a global rate but may pay for services that would be provided in another setting while the resident pays the room and board component and for services provided in the facility that would not be covered as a Medicare service. Over time, HMOs may see the value of covering assisted living services and use the flexibility of their capitation payment to do so. Assisted living facilities could expedite the process by analyzing and documenting the impact that providing services in an assisted living setting might have on health care utilization.

Method

Information for the study was obtained through telephone interviews with officials in each state from state Departments of Health, Aging, and Medicaid to determine whether laws have been passed to create an assisted living licensure category or program, whether regulations have been drafted or promulgated or, if no policy or legislation exists, whether a process is underway to develop and recommend policies. Copies of legislation, draft regulations, final regulations, and reports were received and used as the primary source of information for this report. Follow-up calls were made to states that were in the process of developing recommendations, issuing draft regulations or finalizing regulations just prior to publication in order to present the most up-to-date information available.

MEDICARE HMOs AND REIMBURSEMENT

Assisted living facilities might collaborate with Medicare HMOs on several levels. Assisted living facilities can become part of the network of HMOs with Medicare risk contracts. As networks form, expand, and compete, they seek to maximize delivery of services in the most appropriate and cost-effective manner and to enroll new

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TABLE 1
MEDICARE PAYMENT RATES TO TEFRA
HMOs IN SELECTED AREAS

	Females - 85 and older			
	Institutional	Medicaid	Non-Medicaid	Working
Boston	\$1250.82	\$1173.05	\$725.86	\$519.75
Denver	\$986.21	\$922.45	\$572.66	\$410.99
Mesa	\$690.62	\$644.16	\$401.28	\$288.82
Miami	\$1407.87	\$1262.61	\$825.25	\$616.74
Sarasota	\$872.19	\$795.90	\$509.29	\$374.50
Females - 80-84 years old				
Boston	\$1250.82	\$995.90	\$649.71	\$455.82
Denver	\$986.21	\$784.70	\$513.03	\$360.62
Mesa	\$690.62	\$549.12	\$359.83	\$253.44
Miami	\$1407.87	\$1108.57	\$749.33	\$541.92
Sarasota	\$872.19	\$689.71	\$459.94	\$328.88
Males - 85 and older				
Boston	\$1375.58	\$1481.98	\$821.46	\$593.00
Denver	\$1085.69	\$1166.37	\$648.22	\$469.34
Mesa	\$761.11	\$815.23	\$454.34	\$330.00
Miami	\$1574.57	\$1618.56	\$937.48	\$709.72
Sarasota	\$969.23	\$1014.46	\$577.72	\$429.65
Males - 80-84				
Boston	\$1375.58	\$1371.26	\$755.03	\$529.27
Denver	\$1085.69	\$1080.27	\$596.57	\$418.96
Mesa	\$761.11	\$755.83	\$418.70	\$294.62
Miami	\$1574.57	\$1522.29	\$879.72	\$634.90
Sarasota	\$969.23	\$948.10	\$537.90	\$384.03

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members. Assisted living facilities offer advantages in both arenas. Competition forces HMOs to seek new opportunities and marketing costs for Medicare beneficiaries and can be high because of the more individualized strategies and one-on-one encounters. Strategies that facilitate presentations to groups will reduce marketing costs.

Assisted living facilities offer space to HMOs to provide services. Nurse practitioners, physicians, home-health providers, and other practitioners can use the space to deliver care which creates a presence for the HMO that may interest other members in joining.

PAYMENT RATES

Although some HMOs may avoid recruiting Medicare members who are likely to be frailer and use more services than independent beneficiaries, here too there may be several advantages to marketing to residents in assisted living facilities. HMOs may have an added incentive to enroll beneficiaries residing in assisted living settings. HMOs contracting with Medicare receive a monthly payment of 95% of the Average Adjusted Per Capita Cost (AAPCC) for the county in which the beneficiary resides. The AAPCC is calculated separately for Part A and Part B and the combined rates vary widely across states and counties--from \$738.24 in New York City to \$227 in a rural Nebraska county.

The payment is adjusted by age, gender, welfare, and institutional status. Rates for people in an institution are significantly higher than rates for people in the community. The Part A adjustment is 80% for an 85-year old female living in the community but 210% for the same member in an institution. For example, the actual payment for both Part A and Part B for an 85-year female in Denver would be \$986.21 in an institution and \$572.66 in the community. In Boston, the payment rates would be \$1250.82 in an institution and \$725.86 in the community (Table 1).

The Medicare manual describes payment at the institutional rate for any member who has been a resident for a minimum of 30 consecutive days in a skilled nursing facility, swing-bed facility, intermediate care facility, sanatorium, rest home, convalescent home, long-term care hospital or a domiciliary. Issues have been raised as to whether assisted living is covered by any of these terms. Current HCFA policy would not allow payment at the institutional rate because the term assisted living is not included in the definition. Facilities that may be licensed as a rest home or domiciliary home

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but call themselves assisted living would qualify for the institutional rate.

HCFA's definition means that institutional status is not limited to people who reside in a Medicare certified skilled nursing facility. People who receive a lower level of care are considered to live in an institution. Some observers believe that rest homes and domiciliary homes are comparable to assisted living and should therefore qualify for the institutional rate. However, application of the higher rate would be easier if a level of service were defined rather than in terms which are presumed to convey differences that may exist in actual practice. It is not clear how HCFA defines rest home and domiciliary home. HCFA does not have its own definition and uses the Census Bureau as a source.

The 1977 National Nursing Home Survey conducted by the National Center for Health Statistics defines domiciliary care home as follows: "A facility is a domiciliary care home if its primary and predominant function is domiciliary care but the facility has a responsibility for providing some personal care." The survey differentiates between nursing facility, personal care home, and domiciliary care home based on the percent of residents receiving skilled nursing, administration of medications or supervision of medications, personal care with three or more ADLs, assistance with 1-2 ADLs, and offering room and/or board.

The 1985 survey defined nursing homes as "facilities with three or more beds that provide adults, who require it, nursing care or personal care (such as help with bathing, correspondence, walking, eating, using the toilet or dressing) and/or supervision over such activities as money management, ambulation, and shopping." The survey included facilities that were not certified by either Medicare or Medicaid.

The 1991 survey covered both nursing homes and board and care facilities and categorized facilities using terms and definitions established by state licensing agencies (Van Nostrand, 1997). Defining residential care has customarily been the responsibility of states rather than federal agencies. Facilities themselves are identified by state licensure nomenclature and marketing strategies. Although a few states license rest homes or domiciliary homes, more often, other terms, including assisted living, are used that are equivalent to the rest home or domiciliary home setting and level of care. Proponents, therefore, contend that assisted living is similar to the terms specified in the Medicare manual and HMOs enrolling assisted

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living residents should be reimbursed at the institutional rate.

Although current practice allows facilities to receive the institutional rate, HCFA officials have indicated that a policy letter is being developed that will clarify how the definition of institution should be applied to assisted living not covered by the definition. If HCFA allows the higher rate, the service-rich and supportive environment may actually reduce HMO costs compared to similar members who live in their own homes.

Should the existing interpretation prevail, HMOs still have an incentive to enroll dual eligibles living in assisted living facilities. Because of variations in the adjustment factors for Part A and Part B, an HMO in Denver, serving an 85-year old male would receive \$1166 if the member was also a Medicaid beneficiary compared to \$1086 for members living in an institution. Non-Medicaid community residents would earn the HMO payment of \$648 per month. Payment rates for 80-84-year old males is comparable for both Medicaid and institutional status while both rate cells are significantly higher than the cell for non-Medicaid, non-institutional beneficiaries (see Table 1).

Rates for females 80-84 and 85 and over, who are Medicaid beneficiaries are slightly lower than the rates for institutional settings but significantly higher than for non-Medicaid, non-institutional members. For example, in Boston, the rates for 85 and older female members are \$1250.82 in an institution, \$1173.05 for Medicaid beneficiaries, and \$725.86 for non-Medicaid, non-institutional members.

The application of the definition of "institution" for the purpose of reimbursing HMOs is part of a larger controversy over the payment method used to reimburse HMOs. Studies have suggested that the AAPCC adjustments for age, sex, Medicaid, and institutional status fail to predict utilization and Medicare beneficiaries, enrolled in HMOs, use fewer services than beneficiaries remaining in the fee-for-service system.

To reimburse HMOs more appropriately, the administration has proposed a gradual reduction from 95% to 90% of the AAPCC as well as other changes in the payment method. HMO proponents contend that lower costs allow plans to offer added benefits and charge zero premiums creating the incentive for Medicare beneficiaries to enroll. Reducing payments could erode benefits and force more plans to charge premiums. Efforts to modify the payment method and revise the institutional rate cell for assisted living residents enrolled in an HMO could affect the incentive for HMOs to

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market specifically to residents in assisted living facilities.

SEEKING AFFILIATIONS

Assisted living facilities have two primary options for working with managed care networks. Individual facilities can develop relationships with one or more HMOs. However, single facilities, which most likely do not cover the HMO's entire service area, may have less leverage with a plan than an organization comprised of facilities that offer access throughout the service area. To expand their impact, facilities can form their own organization to negotiate arrangements with HMOs.

EXTENDING FLEXIBILITY OF CAPITATION

Managed care plans contracting with HCFA receive a capitation payment for providing the full range of Part A and Part B benefits. Depending on the payment rate and the cost of providing comparable benefits in a fee-for-service environment, added benefits are usually provided. In December 1996, the percentage of plans covering added benefits was physical exams, 98%; vision tests, 90%; glasses, 5%; hearing tests, 75%; hearing aids, 3%; prescription drugs, 62%; foot care, 38%; dental care, 38%; and health education, 24%.

Currently, HMOs view assisted living as a long-term care service which is not covered by Medicare or managed care plans with Medicare contracts. However, plans have flexibility to provide services that meet the needs of their members and substitute services that are appropriate but more cost efficient than traditional covered services. Assisted living certainly fits as a potential provider for the provision of services covered by managed care plans yet the advantages of HMOs of covering assisted living may not be apparent.

Assisted living facilities will have to be prepared to show HMOs the advantages of working with them. Facilities should also be clear about their own expectations and the impact of working with HMOs on their operations. Assisted living facilities that can demonstrate that residents have fewer hospitalizations and skilled nursing stays through improved medication management and other services available from the facility than comparable Medicare beneficiaries in other settings create opportunities for HMOs to use their capitation even more flexibly. HMOs may be interested in paying for some of the service costs for beneficiaries who have risk profiles that predict

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high utilization.

Some of the potential advantages include:

- Providing a safe, supportive environment during a transition from post-acute care to recovery at home;
- Offering a setting in which HMO covered home care;
- Depending on state-assisted living licensure requirements, offering HMOs a more cost-effective method of delivering home care services;
- Providing a supportive housing and services option for HMO discharge planners considering options for people who no longer live at home following an acute illness; and
- Offering a supportive residential option for beneficiaries who can no longer live at home due to the cumulative effects of chronic illness.

Despite the advances in network development, assisted living facilities are not viewed as a provider for Medicare reimbursable services by HMOs. In addition to the lack of Medicare coverage for long-term care services, HMOs are more likely to authorize services according to strict "medical necessity" criteria than may be the experience in the fee-for-service system. Assisted living facilities may not substitute as readily for the Medicare skilled nursing home benefit as for nursing facility care under Medicaid.

Facilities operating in states which allow facilities to offer a high level of skilled care are more likely to substitute directly. States admitting and retaining individuals needing skilled care may contract with certified home-health agencies and operate within state regulations. Regulations in New Jersey and proposed regulations in Hawaii allow a higher level of care to be delivered by facilities than most other states and regulations in other states may allow certified home-health agencies to provide services that the facility itself may not. Assisted living may also be an appropriate setting for the provision of home-health services when individuals are not able to function safely in their own homes.

The prospects for developing relationships between assisted lived facilities and HMOs is largely conceptual and offers a number of opportunities and barriers as shown in Figure 1.

In fiscal 1994, long-term care comprised 35% of the total Medicaid expenditures. Elderly recipients accounted for 11.5% of total recipients and just under 32% of all spending. Expenditures per

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FIGURE 1
PROSPECTS FOR DEVELOPING RELATIONSHIPS
BETWEEN ASSISTED LIVING FACILITIES AND HMOs

Opportunities

- Reduce HMO marketing costs.
- Site for delivering primary care.
- HMOs obtain higher payment from HCFA for assisted living residents.
- Service rich setting for delivering covered health services that substitute for higher cost services.
- Flexible capitation payment allows coverage beyond traditional services

Barriers

- Medicare freedom of choice limits assisted living facility's ability to "steer" residents to one HMO.
- Space may not be available.
- HCFA may revise the payment methodology.
- Assisted living facilities may not cover an entire service area and may need to develop a network of similar facilities.
- HMOs are not responsible for long term care and may not see the substitution value of assisted living

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recipient averaged over \$9400 of which \$7000 was spent on long-term care. Just over \$6000 of the long-term care spending paid for care in a nursing home (Liska *et al.*, 1996). These patterns highlight the importance of addressing long-term care spending for elderly recipients and acute-care spending for disabled recipients for states interested in controlling Medicaid spending.

Medicaid is increasingly becoming a source of financing for low income assisted living residents. Most states covered assisted living as a home- and community-based waiver service while Massachusetts, New York, and North Carolina covered services in assisted living as a state plan service. In addition, six states, Colorado, Georgia, Missouri, Montana, Nevada, and Vermont, reimbursed personal care services in board and care facilities. State plan services are available to any Medicaid recipient meeting the qualifications to receive services. Medicaid waiver services are limited to recipients meeting the nursing home level of care criteria and spending caps may limit the number of recipients who receive services.

State policy-makers are turning their attention to capitated care programs which include long-term care services to serve aged and disabled beneficiaries. By the end of 1996, at least 30 states were planning or developing managed care programs that included acute- and long-term care and most were considering combining Medicaid and Medicare services to create a fully integrated program. Arizona operates a capitated long-term program and Minnesota was scheduled to implement a voluntary managed care program in January 1997 which capitates both Medicare and Medicaid services for dual eligibles. Florida's Medicaid program developed a managed long-term care pilot in two counties. Colorado has a similar program pending before the U.S. Health Care Financing Administration that would also capitate acute- and long-term care services. Wisconsin operates a demonstration program in two sites that also capitates Medicaid long-term care services.

Although twenty states enroll elderly Medicaid beneficiaries in managed care programs, few include long-term care services in the capitation payment. In 1989, Arizona became the first state to implement a statewide, capitated managed long-term care system (Riley and Mollica, 1996). The Arizona Long Term Care System (ALTCS) serves about 11,000 elderly Medicaid beneficiaries. After a successful three-year demonstration program operated by the Maricopa County Managed Care System, ALTCS contractors statewide will include assisted living facilities among its providers. In

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1996, the legislature approved the statewide expansion of the program and provided funding for 700 ALTCS members and no restrictions on the number of private pay residents. After 1997, there is no limit on the number of members who can be served through Supportive Residential Living Centers.

The Minnesota Senior Health Options (SHO) program is a federally approved Section 1115 waiver demonstration program that will combine Medicare and Medicaid acute- and long-term care services in a five county area. Managed care plans will receive a capitation payment from Medicaid and Medicare to provide all covered services. Assisted living is a service that is covered under the state's 1915(c) Home and Community Based Waiver services program and will therefore also be covered by plans under the demonstration program. The Medicaid capitation payment creates incentives for using in-home and residential service options by paying higher rates for people in these settings who qualify for nursing home placement. Assisted living facilities could be a valuable resource to facilitate such transitions; however, state officials indicate that low SSI benefits, which must be used to pay for room and board, may limit provider interest in the program.

The Florida Medicaid program has also developed a demonstration program to capitate long-term care services through two HMOs in Dade and Broward County. The Independence Plan, which was operated by Pacificare and has been discontinued, developed a unique arrangement with board and care assisted living sites.¹ The plan contracts with assisted living facilities to assist in maintaining members' independence in residential settings in order to prevent or delay nursing home placement or hospitalization. Assisted living providers meet periodically with HMO care managers to discuss member needs, provide space for care managers to interview members, and provide access to member records.

Assisted living facilities are also required to notify the plan of address changes, hospital or nursing home admissions, discharges, storing and tracking health supply inventories, provide additional assistance to people who are incontinent, and verify service delivery by other subcontractors such as home-health agencies. Facilities meeting the plan's standards receive an administrative fee of \$50 per member per month for assisting with these responsibilities.

Assisted living facilities can potentially influence decisions by residents to join an HMO and ALFs are recognizing their emerging leverage. One facility discovered that 15 of its residents were

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members of one HMO. The ALF offered to make office space available and the HMO agreed to send a physician to the site on a regular basis. HMO representatives also noted that ALFs can sometimes create pressure for disenrollment. For example, if the ALF still seeks health services for a resident which are denied by Independence Plan, the staff can encourage the client to disenroll and seek services through the fee-for-service system.

IMPLICATIONS FOR THE FUTURE

As assisted living facilities develop relationships with HMOs, control issues arise and facilities need to have a clear understanding of the respective responsibilities of the HMO and the facility. Among the issues are: who will be responsible for case management and care planning? Each partner traditionally plays a role in conducting an assessment and determining what services are needed and will be provided to a resident. Delineating role here is clearer since the activities of each partner are likely to relate to different aspects of the resident's needs and the respective responsibilities of each to provide services. Developing a plan for a hospital or nursing home admission or discharge may be more complicated and the roles harder to define. An HMO has the incentive to assist a member in moving to the most cost effective and appropriate setting. An HMO may feel that an admission to a hospital or nursing home is not necessary while the facility still believes that the resident's needs can be addressed by added home health care in the facility.

On the other hand, the exact opposite scenario can also occur with the facility staff advising that services be added in the facility while the HMO feels that the level of care needed warrants placement in a nursing home. Likewise, discharges from facilities may also involve different perspectives on what is needed and what setting is most appropriate. The party that has the financial risk is more likely to have the final decision. While the HMO may be at risk for the capitation payment, the assisted living facility may feel pressured by its own liability as well as state regulations that could form the basis of conflict. While these issues are likely to arise, the parties should have a clear understanding of their respective roles and the process for making decisions.

To develop relationships with HMOs, assisted living facilities will need to prepare. First, understanding the cost structure will be critical. Since HMOs aggressively negotiate rates, facilities need to be

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sure of the level of need and cost of providing services for prospective HMO residents. Facilities will also need to develop "products" describing what an HMO will be buying. Understanding the market is also essential. How many HMOs operate in your market? Additionally, of these, how many have or plan to seek risk contracts to serve Medicare beneficiaries? As a facility, do you want to work with one HMO or all the HMOs in the area that serve Medicare beneficiaries? Facilities seeking to contract with multiple HMOs may have to negotiate "most favored nation" agreements prohibiting facilities from negotiating a lower price for the same package of services with a competing HMO. Further, independent assisted living facilities may not cover an HMO's complete service area or they may have sufficient capacity to negotiate with HMOs. Joining forces with assisted living facilities in the area expands coverage and increases leverage with HMOs. While facilities cannot direct residents to join an HMO, a consortium of facilities creates a larger potential market for HMOs as well as a more effective network of providers.

Assisted living facilities should also review the HMO's accreditation. If accredited by the National Committee for Quality Assurance (NCQA), facilities should review the standards and determine how they might apply to their participation in the network. NCQA has set standards for quality improvement, physician credentials, members' rights and responsibilities, preventive health services, utilization management, and medical records.

Despite the extensive discussion of managed care and assisted living, the development of relationships between HMOs and assisted living facilities are still relatively few in number. Relatively speaking, there are more examples of assisted living being part of an integrated network or integrated service delivery than actual reimbursement from an HMO to a network with assisted living facilities or individual facilities. Current federal and state policy and HMO network development suggests the following:

- The emergence of assisted living facilities in managed care has significant potential and is likely to influence the direction of at least a segment of the assisted living industry.

- Formalized reimbursement arrangements between assisted living and HMOs are likely to emerge between facilities that offer a high level of health services seeking to serve higher acuity residents and HMOs with experience enrolling frailer Medicare beneficiaries and with a philosophy

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that emphasizes flexibility and continuity of care in the least restrictive setting than "medical necessity."

-While the majority of HMOs with Medicare risk contracts may be reluctant to reimburse for assisted living, however, collaborative activities may be easier to develop as a means of establishing a working relationship from which more extensive arrangement may develop over time.

-Enrollment of Medicare beneficiaries in HMOs will expand in selective states and within specific areas of some states. The potential for arrangements between assisted living facilities and HMOs will follow the market and will not develop nationally nor ever statewide in states with sizable HMO enrollment.

-As Medicare HMO enrollment expands and as current enrollees age, the number of elders with functional limitations needing a supportive residential setting will also grow which is likely to stimulate interest among HMOs in developing relationships with assisted living facilities.

-State Medicaid programs developing capitated managed care programs for aged Medicaid beneficiaries are a more likely payer for services in an assisted living facility. However, beyond Arizona and Minnesota, these programs will take several years to develop, receive HCFA approval, and be implemented.

The future of such financial arrangement may depend upon a number of factors.

-If assisted living is reimbursed as a substitute for a higher cost setting, how many facilities will seek to serve residents needing more health and medical services?

-Do the regulations governing assisted living in a state encompass or allow the level of care that the HMO seeks for its members?

-How fast will state Medicaid programs implement, with federal waiver approval, capitated, managed long-term care through HMOs that will cover assisted living? and

-Will assisted living facilities, that presently serve an upper-income, private pay market, serve a lower-income, higher need population?

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NOTES

1. Assisted living in Florida includes adult congregate living facilities and extended congregate care. Recent legislation refers to both models as assisted living. ALFs provide meals, housekeeping, and limited personal care. ECC provides a higher level of service and includes some skilled nursing services.

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LONG-TERM CARE DESIGN: STRATEGIES FOR PLANNING THE NEXT GENERATION OF ASSISTED LIVING FACILITIES

VICTOR REGNIER, FAIA

My work over the past few years has focused on identifying residential models of group living arrangements for very old, frail people.

I'd like to begin with a definition of *assisted living*. "Assisted living is a long-term care alternative that involves the delivery of professionally managed personal and healthcare services in a group setting that is residential in character and appearance. It has the capacity to meet unscheduled needs for assistance and does so in ways that optimize the physical and psychological independence of residents."

What does this mean? Let's start with the first sentence — it "is a long-term care alternative." What this implies is a replacement of traditional skilled nursing arrangements in the United States. Assisted living has, in its very short life, become a significant term in the long-term care lexicon.

It "involves the delivery of professionally managed personal and healthcare services." Even though assisted living captures some of the "home-like" characteristics of the best board and care homes, one of the major differences is that assisted living relies on well-trained individuals to care for residents.

"... that is residential in character and appearance." This is something you won't find in other definitions because policymakers don't know exactly what it means or how to measure it. The major element you should take away from this meeting is that *design professionals are an important part of this paradigm shift*. Design plays a very important and significant role in this particular housing and service combination.

"It has the capacity to meet unscheduled needs." This is important as well. People don't decide in advance when they need to go to the bathroom or when they are going to fall. As a result, we

need to attend to an individual when he or she requires assistance.

"... and does so in ways that optimize the physical and psychological independence of residents." One of the major differences between skilled care and assisted living is the dignity that is afforded by risk. Older people and their families want independence and control. They are not particularly interested in a side-by-side hospital-like bedroom. They want their loved ones who are old and frail, whether its mentally or physically frail, to optimize their physical and psychological independence.

Interest in assisted living is being driven by the current population dynamics of the United States. Between 1990 and 2010, there will be a doubling of people who are 85 and older, and by the year 2050, there will be a doubling again.

These are relatively conservative midlevel census projections that show a fourfold population increase in those over the age of 85. The real change is more likely to be 7 to 10 times the current population, which is about 4.5 million. So it's possible that more than 45 million people will be over the age of 85 in the year 2050.

The costs that are associated with this explosion of people over the age of 85 are extraordinary. Alice Rivlin, the head of the U.S. Office of Management and Budget (who was formerly involved in doing community care research for the Urban Institute), has said that we're going to see long-term care costs triple in the next 15 years in inflation-controlled dollars — from \$33 billion to \$100 billion a year. This is significant for assisted living because it delivers housing and service about a third less costly than traditional long-term care.

There is also a great deal of change affecting the regulation of assisted living. Each state is treating this differently, and a lot of experimentation is going on.

Assisted living projects in Oregon have developed as a result of an agreement with state government that involves moving people from nursing homes into an assisted living arrangement at a savings of between 25 and 30 percent to the state. About 40 percent of the people at The Radcliff House, a facility in Canby, Oregon, came from skilled nursing arrangements or intermediate care beds at a savings to the state government. This experiment opened the eyes of many policymakers and politicians.

Most of the innovative work in assisted living now is in the private-pay arena. In Europe, the most inventive projects are subsidized by the government.

One important principle has involved learning from previous projects. Employing the new knowledge and experience gained has allowed these older projects to inform new work. Most planners, especially those from large organizations, are using cascading methodologies that utilize postoccupancy evaluations to inform them about useful adjustments. Even if a prototype is well understood, they rarely build exactly the same project the 2nd, 3rd, or 15th time.

Paul Klaassen, president of Sunrise Assisted Living, has stated that "the assisted living projects of today are not what we're going to be building five years from now. The future will present us with an entirely different set of circumstances — what we're doing today is on the steep end of the learning curve." The fact is, the changes that have occurred in the past three to five years are extraordinary.

The October 1995 issue of *Provider* magazine lists 10 companies that have a total of 350 projects planned between now and the year 2000 — each expected to cost \$4 million to \$8 million.

The Marriott Corporation claims that it is going to build 100 projects by the year 2000. Currently, it has 11 Brighton Garden projects in the United States and 12 full-service communities.

Manor Care currently has 12 Spring House projects, which are mostly acquisitions it has "polished up," and five Arden Court facilities. Executives believe they will have 90 facilities by the year 2000. Sunrise will build 40 projects in the next two years.

Characteristics of Good Facilities

The following nine characteristics are associated with the best assisted living projects:

1. *Residential imagery.* The precedent for assisted living is residential housing. Many successful providers have started with the bed-and-breakfast hotel as a point of departure. The "mother" of assisted living is the single-family house or the apartment building.

2. *Built on a smaller scale.* Assisted living facilities are smaller-scaled arrangements than nursing homes. Most of the facilities have between 40 and 80 units, and 20 to 60 is the preferred range. We need to have a size that is large enough to accommodate the fixed costs of professional management, which is becoming even more important as we see higher levels of acuity in these particular projects.

3. *Regard the person as a unique individual.* This is different from the standard skilled care approach, where only one reimbursement level exists. In assisted living, there is more understanding of the person from a standpoint of how the caregiving plan is structured, and how he or she interacts with other people and the staff.

4. *Involve the family.* This is probably the biggest problem in traditional skilled living arrangements. In assisted living, the family is involved, not just socially, but in an integrated caregiving way. Family members play an important role in the discussion of care and often in direct caregiving.

5. *Focus on mental and physical stimulation.* Many assisted living facilities are joint ventures with other rehabilitation specialists to increase the overall physical and mental competency of the older people living in these settings.

6. *Create a residential environment that has privacy and completeness.* This means avoiding two people in a small, 240-square-foot room with beds that are next to one another. Units should have at least a kitchenette, a space that's large enough to accommodate somebody for an overnight stay, and a full bathroom. We are talking about a housing unit that is linked to a service plan.

"We should expect 40 percent of the residents to have some mental impairment and 40 percent to be incontinent ..."

7. *Maintain connections with the surrounding community.* When we think of nursing homes, we often think of them as institutions. When we conceptualize institutions, they are, by definition, separated from context.

8. *Foster independence, interdependence, and individuality.* Earlier, I mentioned the importance of independence. Interdependence involves helping one another — not just residents helping residents but through volunteerism helping others who live in the facility. Older people can help establish an informal network of care and support. When people are treated as individuals, they are able to maintain their sense of individuality within this context.

9. *Focus on the older, frail person.* A proper assisted living facility should be serving a very frail population. We should expect 40 percent of the residents to have some mental impairment and 40 percent to be incontinent or have troubles with incontinency. This is not very different from what we expected a nursing home population to be 10 years ago.

Community Design

One of the most interesting aspects associated with the European projects is the way they are integrated with the surrounding community context.

The more that I hear from managed care providers and others who are discussing community care, the more I believe they are describing the types of assisted living models common throughout northern Europe. The service house is a place in the community, often linked to a particular neighborhood, that incorporates a multitude of land uses. It often includes housing for the frail, a senior center, a restaurant, a home health agency, an infirmary (which also provides respite care), and an outpatient physical therapy space.

The European service house combines all of these uses and serves two distinct audiences. One group of services is provided to people who live in the surrounding neighborhood. Eighty of the 100 European projects I discuss in my book had publicly accessible restaurants that people from the surrounding neighborhood could use. They also "manufacture" services for people living in the surrounding community.

Often, older people living in the community are linked to the service house by a tele-alarm or "lifeline" emergency response system.

The service house is becoming a very appealing model. In fact, in working with the 50 state units on aging and the 600 area agencies on aging, we find that many of them are highly motivated to assemble service delivery arrangements. This makes sense because it provides the opportunity to "push" people back into the community and keep them independent for as long as possible. When it is no longer feasible to manage them at home, then we can take care of them in an assisted living arrangement.

There are many mixed-land-use models, including a facility in a small town called Monster, which is near Amsterdam. This 60-unit service house is next to an outpatient care facility. Across the street, there is housing that "leans-to" the service house — again, linked electronically through lifeline systems and serviced by healthcare and home health workers at the service house.

Another elderly service house facility in Helsinki has a childcare center. In fact, in northern Europe, childcare and adult care are coordinated by the

same agency and are often mainstreamed together. They think of the two ends of the dependency continuum as fitting into the same broad-based service delivery system.

A suburban facility in Sweden has the service house above an existing shopping center. Another facility, in Denmark, is located between a hospital and the train station. People going to the hospital walk through a series of courtyards from the train depot to the front entrance of the hospital. Social spaces in the service house overlook the activity generated along this courtyard street.

Another service house in Sweden is designed so that it shares a gymnasium and a crafts room with an adjacent middle school for children. The gymnasium can also be shared with older people who are living in the surrounding community. Intermixing these two programs saves money and also creates all kinds of interesting possibilities for social interaction.

Administrative Oversight

One of the more omnipresent characteristics of U.S. nursing homes is the nurse station. Since our regulations require a maximum 90-foot distance from the nurse station to the portal entry of the unit, most nursing homes are pretty predictable X-, L-, and T-shaped double-loaded corridor schemes. Denmark and Sweden never had those regulations, so they didn't design their facilities as double-loaded corridors with a single nurse station.

When I talked with nurses in Europe about how we design nursing homes in the United States, they said things like, "Well, that would be kind of ugly, wouldn't it? Why would you want to have all those dark corridors with no natural light? Here, we decentralize the care. Why wouldn't you do that? Most people are out on the floor, so who cares who's at a central nurse station?"

These are very rational and sensible criticisms of a model that doesn't make much sense anymore, but has been allowed to proliferate because of regulations. It is being rejected by consumers, and as we move to a system where consumer choice is going to be the primary component, it is an endangered model. For frail older people, their children often make the placement decision.

We're going to see increasingly greater sensitivity and more environments that are humane, appropriate, and sensible. A nurse station in Sweden is an alcove with a table. People roll their wheelchairs to the edge of the table or walk up to it and sit down. It is approachable — a model for openness and connectedness. It doesn't have a 42-inch-high counter that separates the nurse from the view of the residents. It is much more focused on caregiving than on paperwork accountability.

A project in Framingham, Massachusetts, uses the kitchen as the nurse station. We are seeing all kinds of interesting ways in which the nurse station is evolving, but the food preparation area of the unit is often becoming a central focus.

The local nursing home, Sweden's first approach to decentralizing care, featured 32 units split up into clusters of eight residents each that opened onto smaller dining room spaces. The nurse station is a small alcove off to the side where one can go if one needs to be by oneself, do charting, or make phone calls.

In Denmark, medical records are kept under lock and key in a drawer someplace, and a social record (which outlines a description of what was occurring that day, what some of the problems were that needed to be attended to, what medication changes were occurring that the next shift needed to pay special attention to) is available to anyone. It's like a diary. Nurses write in it, older people sometimes write it. They share information from one shift to the other, in a way that's quite natural.

Most of the projects I visited were single-loaded corridors that were decentralized and clustered. It's not at all uncommon to find projects that are open to the corridor edge and natural light. When I asked, "What do you do at night, when you've got to cover more territory?" They showed me scooters they used to make the nursing staff more mobile. They said, "We're the mobile ones. The older people we're helping stay in one place and we try to make these little clusters work like little housing arrangements so that they all have friends and they can have a much more intimate social life. But we can get from one place to another rather efficiently."

Landscape Architecture

It is surprising to me that we see more effective and therapeutic use of outdoor spaces in the upper reaches of Norway, Finland, Denmark, and Sweden than in the Sun Belt area of the United States.

The two basic examples we always think about are the courtyard-shaped building, where there is an urban edge on the outside and most of the garden space is in the center, and the building that is situated in the middle of a landscaped area, like a single-family house.

In the Netherlands, there are *hofjes* that house women who are widowed. In one example, 29 women live around a courtyard that is linked to a medieval street. One walks through the entry and emerges into a beautiful courtyard that is quiet, green, and socially conducive.

Woodside Place in Oakmont, Pennsylvania, a suburb of Pittsburgh, features three small bungalows

of 10 dwelling units. Each bungalow house has a connection to a small garden that helps to define the place.

A garden can be a good destination space. A facility in Finland has a birdcage in the middle of an atrium, which is a rationale for visiting the atrium.

The Motion Picture Country House in Woodland Hills, California, has one of the best Alzheimer's wandering gardens in the United States. It's about an acre and a half, with a looped pathway and two different ecologies. It is arranged so that (1) residents can't get lost, and (2) there is a lot of variety in the kinds of experiences they have — different plant materials are specified; there are different places to sit and watch people and to become a part of the activity.

"It's important to use atria and gardens for activities."

Older people who are very frail in assisted living can't get into the neighborhood. They can use the site, and with some assistance, they can take a little walk around the building. So outdoor spaces adjacent to the building and indoor spaces that overlook outdoor areas are important.

Many facilities have outdoor spaces that are closely coupled to the perimeter of the building, such as an arcade, porch, or balcony. They also have greenhouse spaces inside and spaces that are visually connected to the surrounding neighborhood.

Many facilities located in northern latitudes like to take advantage of daylight because it gets dark early in the winter. It's not uncommon to find skylights with plant materials.

An atrium in the center of one nursing home had a rolling roof that covered it in the winter so that the space could be used when it's cold outside. It's important to use atria and gardens for activities.

The Rosenberg Nursing Center near Copenhagen, Denmark, uses its atrium to promote the tradition of taking morning and afternoon coffee, which is a salient social activity in this culture. They have taken the best space in the facility and have centered it on a behavior that is very popular and so the space is used every day.

A facility in Holland features eight units designed around an enclosed but not air-conditioned corridor, which is designed as an outdoor space. There are concrete bricks and plant materials in the corridor, and everything is connected to a two-story atrium with skylights on the upper floor, which allows light to penetrate to the lower floor.

Another facility in Holland has a two-story arrangement with a skylighted central spine. The single corridor in the center is bridged to units on both sides.

The last example is a three-story atrium where the corridor is on one side with a bridge that connects two units on the opposite side to the corridor. The idea, of course, is that the light comes through, and since each floor is a little bit wider, it's possible for light to penetrate to the first floor.

Privacy & Therapy

Personalization at the unit can add variety and uniqueness. A Dutch door can provide a connection between the unit and the public spaces, as well as some privacy.

In the De Overloop project, European architect Herman Hertzberger used street addresses to treat each corridor as a street. Windows and Dutch doors create a socially conducive cluster for units, because people are all sharing the same alcove.

In Annapolis, Maryland, Sunrise used double-hung windows and skylights in a central corridor neighborhood. These provide a transparency of natural light in the center of the corridor and also the possibility of a view through the unit and light from the opposite sides.

Therapy is an important issue in designing assisted living facilities that I don't think is operationalized as effectively in skilled nursing arrangements.

A facility in Finland has placed physical therapy equipment and activity in the middle of its atrium. It's very visible to residents who are living above it. When they see it, they recognize that there is an obligation to be involved in therapy and that part of their contract is to keep themselves as competent as they possibly can within this context, so that they are not using services they don't need.

A small group home in Sweden offers a unique way to deal with people who have memory impairments. The Danes have tried (without a great deal of success) to mainstream older people with Alzheimer's with physically impaired individuals. The Swedes de-

cided they wanted to move most of their older residents with Alzheimer's into small group homes of six to eight units each.

In this example, the small group home for six older people is in the angle of the "L" on the first floor, and is surrounded by nearly a dozen units of family housing. In the mixed-use project the family housing uses the inside courtyard, and on the opposite side is a wandering garden for people with Alzheimer's.

Assisted living is changing the way we perceive housing, health, and personal care provision for older mentally and physically frail people. It is gradually but progressively challenging the position of the nursing home as a central element of the long-term care system in the United States. As more older people and their families insist on housing that respects privacy, nurtures the spirit, saves them money, and provides more choice and control, assisted living will grow in popularity.

Many challenges remain. The entitlement of assisted living for moderate- to lower-income people seems to be one of the highest priorities. In Europe, assisted living has been viewed as a way to save money and provide consumers with a needed alternative. Regulations will follow entitlements. We must design a system of care for the next century that is sensitive to consumer demands and does not prematurely restrict itself through outmoded regulatory strategies that stifle innovation.

The next 10 years will bring unprecedented growth in the older-old population and the number of assisted living facilities. Design professionals will play an important role in helping to usher in this major paradigm shift. The design of the environment will continue to play an extremely important role by providing a supportive and humane setting for the evolution of this housing and service type.

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Coalition of Assisted Living Providers and Consumer Organizations Agree on Quality Initiative

WASHINGTON, DC - After two years of research and collaboration, a coalition of six organizations representing assisted living providers and consumers announced agreement today on the first-ever national quality initiative for the assisted living industry. The coalition recommendations have been released in a new document entitled Assisted Living Quality Initiative: Building a Structure that Promotes Quality.

"The Assisted Living Quality Coalition (ALQC) has been working together to develop a framework to ensure that the needs and preferences of the consumer remain at the center of the delivery of assisted living as the industry grows and matures," says Coalition representative Ruth Gulyas. "The report reflects our belief that the core of any effort to preserve the assisted living model in the future must focus on ensuring providers retain the needed flexibility in the provision of assisted living services. Quality improvement efforts must focus on key outcome measures."

The Alzheimer's Association and the AARP, both with members who live or may someday live in assisted living settings along with the American Association of Homes and Services of the Aging, American Health Care Association's National Center for Assisted Living, American Seniors Housing Association, and the Assisted Living Federation of America all whose memberships provide assisted living, have worked for over two years to develop the initiative.

Coalition members hope the initiative will offer a new way for consumers, providers, government and third party payers to work together to provide a system that serves the unique needs of each resident. The goal of the initiative is to provide an innovative and efficient monitoring and improvement system focused on achieving outcomes to better meet individuals' needs and preferences.

One part of the initiative being agreed to today are guidelines for states on minimum standards for assisted living. One strength of assisted living is that it has developed to serve the unique needs of each state, these guidelines can be a resource for states as they develop

their own standards. Currently, 16 states are developing or studying their assisted living regulations.

"As greater numbers of each state's older residents move into assisted living settings, state governments recognize the importance of the industry," Gulyas says. "The guidelines provide a definition of assisted living, and for the philosophy, services, environment, consumer protections and management responsibilities offered by assisted living providers."

The initiative also commits Coalition members to study the feasibility of establishing an independent National Assisted Living Quality Organization (NALQO). The proposed NALQO would develop information sources and manage the quality improvement system the Coalition proposes for the future. It will also periodically review the guidelines to keep them up to date.

As the Coalition studies the feasibility of using the proposed quality outcome measures and establishing a national quality organization, members will also be promoting the initiative through their own member networks. ALQC members will work to encourage states to use the guidelines as a resource in developing their own quality programs for assisted living.

The Assisted Living Quality Coalition, consisting of the Alzheimer's Association, the American Association of Homes and Services for the Aging, AARP, the American Health Care Association's National Center for Assisted Living, the American Seniors Housing Association and the Assisted Living Federation of America, believes that: to provide the highest level of quality and consumer satisfaction in assisted living, the assisted living industry must have a consumer-oriented, performance-based system for quality improvement; the most effective quality initiative for assisted living will be developed collaboratively between consumers and providers, with input from other assisted living stakeholders.

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