GRANT MAKERS IN HEALTH

# LONG-TERM CARE QUALITY

## *Facing the Challenges of an Aging Population*

ISSUE BRIEF NO. 6

BASED ON A GRANTMAKERS IN HEALTH ISSUE DIALOGUE

WASHINGTON, DC

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# Foreword

As part of its continuing mission to serve trustees and staff of health foundations and corporate giving programs, Grantmakers In Health (GIH) convened a select group of grantmakers and national experts who have made a major commitment to improve the quality of long-term care, particularly the care provided in nursing homes. The roundtable explored various factors influencing both the quality of care provided to elderly patients, as well as the quality of their lives. The discussion ultimately centered upon the importance of grantmaker involvement to improve the quality of long-term care, including the services delivered, training for professional and paraprofessional staff, continued research and evaluation, and public policies regulating the long-term care industry.

This report brings together key points from the day's discussion with factual information on demographic, financing, and public policy trends drawn from a background paper prepared for the meeting. When available, recent findings, facts, and figures have been incorporated.

Special thanks are due to those who participated in the Issue Dialogue but especially to presenters and discussants: Steve Dawson, Judith Feder, Cynthia Graunke, Catherine Hawes, Karen Hicks, Mary Jane Koren, William Read, and Robyn Stone. The meeting was chaired by Lauren LeRoy, president and CEO of GIH.

Kate Treanor of GIH's staff planned the program and wrote the initial background paper. Anita Seline skillfully synthesized the background paper with points made at the meeting. Anne Schwartz and Leslie Whitlinger of GIH also contributed to the final report.

GIH also gratefully acknowledges The Commonwealth Fund for its support of this program, the fifth in a series of forums designed to bring grantmakers together with experts in policy, practice, and research to exchange information and ideas about key health issues.

# About GIH

Grantmakers In Health (GIH) is a nonprofit, educational organization dedicated to helping foundations and corporate giving programs improve the nation's health. Its mission is to foster communication and collaboration among grantmakers and others, and to help strengthen the grantmaking community's knowledge, skills, and effectiveness. Formally launched in 1982, GIH is known today as the professional home for health grantmakers, and a resource for grantmakers and others seeking expertise and information on the field of health philanthropy.

GIH generates and disseminates information about health issues and grantmaking strategies that work in health by offering issue-focused forums, workshops, and large annual meetings; publications; continuing education and training; technical assistance; consultation on programmatic and operational issues; and by conducting studies of health philanthropy. Additionally, the organization brokers professional relationships and connects health grantmakers with each other as well as with others whose work has important implications for health. It also develops targeted programs and activities, and provides customized services on request to individual funders. Core programs include:

- **Resource Center on Health Philanthropy.** The Resource Center monitors the activities of health grantmakers and synthesizes lessons learned from their work. At its heart are staff with backgrounds in philanthropy and health whose expertise can help grantmakers get the information they need and an electronic database that assists them in this effort.

- **The Support Center for Health Foundations.** Established in 1997 to respond to the needs of the growing number of foundations formed from conversions of nonprofit hospitals and health plans, the Support Center now provides hands-on training, strategic guidance, and customized programs on foundation operations to organizations at any stage of development.

- **Building Bridges with Policymakers.** GIH helps grantmakers understand the importance of policy to their work and the roles they can play in informing and shaping public policy. It also works to enhance policymakers' understanding of health philanthropy and identifies opportunities for collaboration between philanthropy and government.

GIH is a 501(c)(3) organization, receiving core and program support from more than 175 funders annually.

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# Introduction

As Americans age and the need for long-term care services grows, the quality of care delivered, as well as the quality of patient life, will become increasingly important and poignant. At some time, long-term care will affect everyone either as individuals or as family members. "There are few issues that have the gut-level importance that long-term care does. It hits us all," says Judith Feder, dean of policy studies at Georgetown University, "because when people, old or young, need help to manage daily life, it is a powerful, personal experience."

But for all the sophistication of our health care system, the United States does not have a highly developed and supportive long-term care network that takes good care of its elderly. The quality of long-term care services, particularly the care provided to nursing home residents, has emerged as a critical issue over the last few decades. Individuals with long-term care needs seek care from a variety of sources, including informal systems set up by families, friends, and hired home health workers; assisted living settings; and nursing homes. This fragmented system has little consistency in quality, troubling workforce problems, and costs that can bankrupt patients. The ability of our society to provide and pay for this inevitable long-term care, as well as to improve the quality of services delivered and patient quality of life, will become increasingly important in future years.

In recognition of these emerging health and social issues, Grantmakers In Health (GIH) convened an Issue Dialogue on June 15, 2000, to examine the quality of long-term care services, with a focus on nursing homes. The meeting, *Long-Term Care Quality: Facing the Challenges of an Aging Population*, brought together grantmakers, health care professionals, health policy officials, and experts in aging to articulate ways that foundations can work to improve the quality of long-term care.

In developing the program for the Issue Dialogue, quality was broadly defined to include not only services and outcomes, but also the range of activities and interactions that compose the daily life of elderly individuals receiving long-term care. Consistent with the Institute of Medicine's (IOM) definition, quality includes services that gain desired health outcomes, but also those activities affecting the cognitive and emotional well-being of elderly patients, such as treatment for depression or the use of advanced directives. These aspects of quality can be influenced at the organizational, political, community, and individual level.

During the Issue Dialogue, a number of opportunities for grantmakers to positively influence the quality of long-term care services and the quality of patient life were explored. Successful long-term care systems must be analyzed with a focus on replicating critical measures elsewhere. There is a need for more explicit public policy and stronger regulatory enforcement. Foundations can also strive to better the working conditions and pay of paraprofessionals working in long-term care settings. Patients and families, who are often afraid to speak for themselves, must be provided support and advocacy services in order to deal with the intricacies of the long-term care system. Finally, grantmakers must negotiate with all of these constituencies and bring them together to work on a common agenda if the quality of long-term care is to be improved dramatically.

This Issue Brief brings together information from a background paper written for the Issue Dialogue with the discussion among participants at the meeting. It offers an overview of the primary factors influencing the quality of

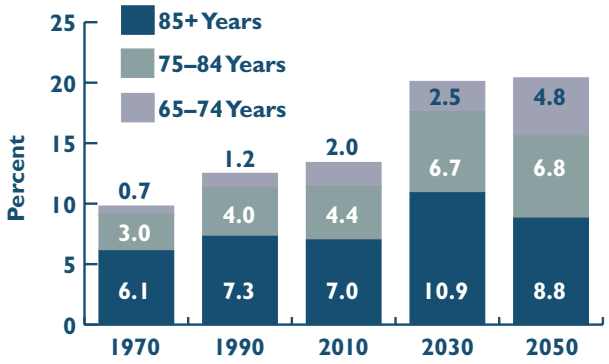
long-term care services, including demographics, service providers, financing, and policy and regulation. The final section of the report highlights innovative grantmaker programs that strive to raise the quality of our nation's system of long-term care for the elderly.

## Changing Demographics: Increasing Demand, Decreasing Caregivers

The number of elderly in the United States steadily grew throughout the 20th century. In 1900, there were approximately 3.1 million people over the age of 65. Today, there are more than 35 million elderly (Friedland and Summer 1999). The aging of the baby boom generation will accelerate this growth significantly, as well as heighten future demand for long-term care services. Increased longevity also means many people may be faced with living with chronic disease and disability for many years. While, in the past, old age meant living to the age of 50 or 60, today it is not uncommon for people to live well into their 80s and 90s (Figure 1).

The likelihood of needing long-term care accelerates with age, due to the increasing prevalence of chronic illness and disabling conditions, both physical and cognitive in nature. Heart disease, stroke, respiratory problems, senile

**Figure 1.** *Elderly Persons as a Percentage of the U.S. Population, 1970–2050*




Demographic changes, particularly increased life expectancy and the aging of the baby boom generation, will dramatically increase the number of elderly in our population. Those over the age of 85 will be the fastest growing segment of our society.

Source: Komisar, Harriet L., Jeanne M. Lambrew, and Judith Feder, *Long-Term Care for the Elderly: A Chart Book* (New York, NY: The Commonwealth Fund, December 1996).

## EXPANDING THE DEFINITION OF QUALITY

In the past few decades, the idea of quality has broadened to encompass not only service provision and medical outcomes but also the social and psychological well-being of patients. This expanded view of quality is evidenced in the Institute of Medicine's (IOM) work on quality assurance in which quality health care is defined as "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge " (Lohr 1990). As McGlynn (1997) points out, this definition not only focuses on the services delivered, but acknowledges the existence of a quality continuum and the ability to evaluate quality from an individual and population perspective. It also suggests the need for research-based evidence to identify services that improve health outcomes and, in the absence of such evidence, the need for professional consensus to develop quality criteria.

Measuring and evaluating quality yields information that can be used to improve performance. Health care professionals, policymakers, and others can use information about quality to:

- understand the effects of health care services and how these effects may differ according to patient population, care setting, and health condition;
- determine how the organization, delivery, and financing of health care affects quality at the individual and population levels; and
- provide consumers with information for making appropriate health care choices (Donaldson 1999).

Measurement and evaluation also serve a range of other objectives. At the organizational level, this information may be used to determine whether a facility meets established standards; to identify and possibly eliminate substandard providers; to highlight, reward, and share best practices; and to monitor and report information about changes in quality (Donaldson 1999). At the health care professional level, information gained may be used to create clinical guidelines and protocols, or to restructure the process of care.

There are many ways to measure quality. In recent work on this topic, the IOM uses long-term care services, specifically nursing home care, as an illustration of the three primary measures of quality: structural, process, and outcomes. Each of these measures is described below (Donaldson 1999).

- *Structural measures* of quality include the characteristics of the health care system's resources, such as facilities, staffing, and training of professionals and paraprofessionals caring for nursing home residents. An evaluation of nursing home staff training and staff availability for patient care, for example, may be used to determine whether the quality of care is adequate.
- *Process measures* include both clinical quality – prevention, diagnosis, and disease management – and the technical aspects of care, such as accuracy of diagnosis, appropriateness of therapy, and coordination of care. The quality of nursing home care may also be measured by assessing problems such as inadequate care plans, the use of physical restraints, or unsanitary food.
- *Outcome measures* include rates of survival, unintended treatment effects, and relief of symptoms. Patient reports about personal health and functional status, as well as patient satisfaction levels are also included.

Ultimately, the IOM and others suggest that outcome measures may be the best form of quality measurement since what providers, policymakers, and families are most interested in is whether the care provided has improved the patient's life.

*Once people start to need these services, they don't get better. Their needs generally grow over time.*

KAREN HICKS,
NEW HAMPSHIRE
DEPARTMENT OF HEALTH
AND HUMAN SERVICES,
JUNE 2000

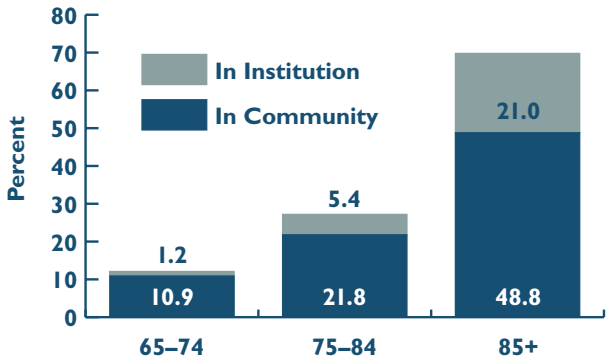
dementia, and loss of hearing, sight, and mobility are common among the elderly. As a result, many elderly people need help with the basic tasks of everyday living.[1] Feder estimates that 12 million people – both young and old – needed long-term care in 1995, though only about 4 million of these people had substantial needs. Elderly patients may be admitted to a nursing home because of a chronic illness or the need for post-acute nursing care. Most also require assistance with multiple ADLs, however. Among the 34 million elderly in 1995, 5 percent were nursing home residents and 12 percent were living in the community with ADL or IADL limitations. The incidence of chronic conditions is significantly higher for the oldest old. Among those 85 and older, 21 percent were in nursing homes in 1995 and another 49 percent were community residents with long-term care needs (Stone 2000) (Figure 2).

Among the most frail and vulnerable aged are the 1.6 million elderly residing in nursing homes. According to the American Health Care Association (1998), the typical nursing home resident is a female in her 80s requiring assistance with four out of five ADLs. The ADLs for which nursing home residents most typically require assistance are bathing (91 percent), dressing (79 percent), getting in or out of a bed or chair (64 percent), using the toilet (64 percent), and eating (42 percent) (Komisar et al. 1996). These physical limitations are frequently accompanied by cognitive impairments such as memory loss and dementia.

Today's nursing home residents are older and more disabled than just ten years ago. A comparison of 1985 and 1995 National Nursing Home Survey data by Bishop (1999) suggests that the less disabled elderly, who 10 years earlier would have been nursing home residents, were residing elsewhere in 1995. This analysis also reveals that the median length of stay for nursing home residents has decreased from 611 days in 1985 to 553 days in 1995.

Shifts in the age distribution within the U.S. population will also profoundly affect long-

**Figure 2.** *Prevalence of Long-Term Care Need Among the Elderly by Age, 1995*




Functional limitations increase substantially with age, particularly for the oldest old – those age 85 and older.

Source: Stone, Robyn I., *Long-Term Care for the Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century* (New York, NY: Milbank Memorial Fund, 2000).

[1]These tasks fall into two categories. Activities of daily living (ADLs) include tasks such as eating, dressing, or bathing. Individuals with substantial needs require assistance with three or more ADLs. Instrumental activities of daily living (IADLs) include assistance with light housework, meal preparation, taking medications, and other tasks.

term care services. Historically, there have been a greater number of younger people in our society with fewer living into old age. By 2030, however, this traditional population pyramid is expected to become a rectangle, with the population more evenly distributed across age groups (Friedland and Summer 1999). Consequently, there will be fewer younger people caring for more elderly. With less younger people and informal caregivers available, the elderly may need to rely more heavily on paid, formal long-term care.

Traditionally, women have been the caregivers in our society, acting as both informal as well as paid caregivers. Women overwhelmingly hold the majority of nursing and paraprofessional positions in long-term care organizations. Yet, because of the demographic shifts discussed above, there will be fewer women aged 25-54 to fill traditional nursing and paraprofessional positions. Just when the demand for formal long-term care begins to escalate, the availability of that care will begin to diminish. This combination of demographic changes – a greater number of people living longer, with more chronic conditions, and a diminishing or, at best, stable workforce – poses serious challenges to long-term care providers, policymakers, and the public, which will only intensify over the next few decades.

## The Many Faces of Long-Term Care

In order to understand how long-term care quality may be influenced, the breadth of long-term services provided to the elderly and the variety of settings in which these services are delivered must be considered. Feder and her colleagues (2000) define long-term care as "a broad set of paid and unpaid services for persons who need assistance because of a chronic illness or physical or mental disability." Stone (2000) elaborates, describing long-term care as encompassing functional, social, and environmental domains, and suggesting it is broader than the medical model dominating acute care services.

Our nation's attitude toward long-term care and acute care are markedly different. Our acute care system is based on the expertise of a number of highly paid professionals with advanced levels of education and technological experience, and can be considered quite sophisticated. For the most part, we trust that health care system and believe that it works, Feder says. People generally do not feel as confident, however, about the spectrum of long-term services. Home-health and in-between services such as assisted living locales are not well-developed or sophisticated sources of delivery. Moreover, the quality of nursing home care is often called into question.

### DEMOGRAPHIC CHANGES

Demographic changes over the next three decades will intensify the need for long-term care services. In a recent analysis of these changes, Feder and her colleagues (2000) note that current projections "suggest that the demand for long-term care among the elderly will more than double in the next 30 years [and that] this growth will exacerbate concerns about balancing institutional and noninstitutional care, assuring quality of care, integrating acute and long-term care, and … adopting financing mechanisms that equitably and adequately protect people who need long-term care."

*Like it or not, there are almost 2 million people in nursing homes in the United States today. Whether or not we develop fabulous home care programs, we are still going to have a need for institutionally based long-term care.*

MARY JANE KOREN, THE FAN FOX AND LESLIE R. SAMUELS FOUNDATION, JUNE 2000

In the United States, long-term care is comprised of a fragmented set of services that runs from informal, unpaid services – typically provided by family and friends – to care provided in institutional settings. Between these extremes lie a host of community-based and assisted living services providing a wide range of medical and social services. The following is an overview of the categories into which long-term care services fall.

## Family Caregivers

The majority of elderly receive informal, unpaid care from family, friends, and neighbors. Despite the fact that families are already stressed, they manage this long-term care for their loved ones with no pay or support. In fact, according to Catherine Hawes, professor at the Department of Health Policy and Management at the School of Rural Public Health at Texas A & M University, from a policy perspective, we count on families to "just cope" when it comes to providing long-term care to loved ones.

But future declines in the availability of unpaid caregivers will place additional strains on our nation's fragmented system for long-term care (Stone 2000). "The idea that we should try and extend the burden on families is not useful," said Dr. Hawes. In addition, few communities are trying to address the degree of anxiety and isolation that families feel when they need assistance.

## Home Health Care

Home care services are designed to help the elderly remain independent and in the community. Typically, home care services encompass both skilled nursing and supervisory custodial care, as well as personal care (bathing, dressing, toileting) and homemaker services (meal preparation, light housekeeping, laundry) (Cox 1993). The vast majority of these services are provided by paraprofessional health care workers such as home health aides.

## Community-Based Programs

Formal community-based programs offer assistance in congregate settings, such as senior centers and adult day care, and enable the elderly to remain in the community. These programs provide both health care and social services. Elderly receiving such services may have contact with a broad array of health care and social service professionals.

A rapidly growing form of long-term care is assisted living. These settings provide personal services, supervision, activities, and health-related services designed to accommodate residents' changing needs. They also strive to maximize resident autonomy, privacy, and independence; and to encourage family and community involvement (The Assisted Living Quality Coalition 1996).

## Nursing Homes

Despite rapid growth in home care, community-based programs, and assisted living, nursing homes are still the most recognized form of long-term care (Feder et al. 2000). Nursing home care includes protective and therapeutic services provided by nonhospital-based nursing homes, intermediate care facilities for the mentally retarded, and Department of Veterans' Affairs facilities (Komisar et al. 1996). Residents tend to be older, sicker, and in need of a wider array and more intensive degree of health and personal care services than those in other settings.

Currently, there are an estimated 17,000 nursing homes in the United States, with a total of 1.8 million beds. These facilities vary by ownership (i.e., for-profit, nonprofit, or government), bed size, services provided, and populations served. Data from the National Nursing Home Survey show that, in 1997, the average nursing

## NEW HAMPSHIRE: BUILDING A BETTER LONG-TERM CARE SYSTEM

The Granite State faces many of the same demographic and labor challenges in providing long-term care as other states, prompting state policymakers to consider initiatives aimed at developing a better long-term care system.

Consider New Hampshire's demographic realities:

- The elderly population is increasing rapidly. By 2005, the number of people who are 85 years old will grow by one-third.
- The state is sixth in terms of per capita wealth but is experiencing a growing divide between the haves and have-nots.
- Long-term care must be provided in both populous and rural areas. Three-quarters of New Hampshire's 1.2 million people live in the southernmost end of the state.
- Nursing home care costs $45,000 annually. Most elderly spend down their resources quickly and depend on Medicaid.

Karen Hicks, policy director for the state's Department of Health and Human Services, said that the development of a comprehensive system of long-term care is one of the top priorities in the department. "Our goal is to really build and support a consumer-centered, consumer-directed, long-term care system," Hicks said.

Creating a consumer-centered system moves away from issues of regulatory compliance and process outcomes. It means that consumers can figure out how the long-term care system works and can make good choices in selecting a long-term care facility. Once there, residents want to feel safe, comfortable, and have a sense of privacy. They want to be in a place where the staff knows when they want to get out of bed, to get dressed, and to bathe.

New Hampshire is working to develop a better continuum of long-term care services. The first stop on this continuum is improved information about long-term care, including healthy aging, financial planning, and long-term care insurance. Next, the state wants to develop better support for family caregivers, such as training, safety assessments, and benefits and stipends. Supplemental care must be broadened, as well, providing homemaker services, transportation, and respite care to informal caregivers. Community and medical support of in-home care would include assistive technology, nursing, and therapy services.

Final steps along the continuum include a fully developed system of community-based care, such as congregate housing and institutional care. New Hampshire also wants to focus on end-of-life care with better utilization of hospice programs.

New laws have been enacted to help develop this continuum of care. Hicks said the state now provides for Medicaid payment for personal care and allows the patient to choose a provider, such as a neighbor or family member, to help with such intimate services as bathing, grooming, and feeding.

Another recent law requires nonprofit organizations, such as health care facilities, to develop community benefit plans explaining how they help their communities. These plans detail whether a hospital, for instance, is paying its workers living wages and providing them health insurance.

Lastly, the state is reviewing other policy initiatives that will help build this long-term care system, much of which will center on workforce development.

*The direct care worker is the hands and the face and the voice of care for literally millions of long-term care residents and citizens.*

STEVEN L. DAWSON, PARAPROFESSIONAL HEALTHCARE INSTITUTE, JUNE 2000

home had 107 beds and an occupancy rate of 88 percent (Gabrel 2000). Additionally, there were 1.6 million nursing home residents and 2.4 million discharges. These averages, however, mask the variability among nursing homes. One illustration of this variation is facility ownership. In 1997, 67 percent of nursing homes were for-profit, while 26 percent were nonprofit and 7 percent were government owned (Gabrel 2000). Nursing home bed size also provides an excellent example of variation. In 1997, 13 percent of nursing homes had fewer than 50 beds, compared to 37 percent with between 50 and 99 beds and 42 percent with between 100 and 199 beds. Just 8 percent of nursing homes had more than 200 beds.

In America, there is a certain ambivalence when people think of nursing homes. Although nursing home utilization rates are the same in the United States as is in other industrialized countries – about 5 percent of the population – most Americans would say they do not want to end up in one. "I'd like to make nursing homes the type of place that people don't say, 'I'd rather die than go there,' which I think public policy could actually do," said Hawes. According to Hawes, this segment of the population has few alternatives in long-term care. Half of nursing home residents have outlived all family members. Two-thirds suffer from cognitive impairment; two-thirds have urinary incontinence; and many have four to five chronic diseases and disabilities.

## Nursing Home Staff: Better Employees = Better Quality of Care

Nursing staff provide most nursing home care. In 1997, paraprofessionals, such as nurses' aides and orderlies, accounted for approximately two-thirds of total nursing staff, while registered nurses (RNs) accounted for only 15 percent. Less than 7 percent of total nursing home staff is comprised of medical, therapeutic, and administrative personnel (Gabrel 2000). Of the approximately 950,000 full-time nursing staff, paraprofessionals provide the vast majority of direct care. In fact, nurses' aides and other attendants provide between 80 percent and 90 percent of the direct care for nursing home residents (Wilner 1999).

Workforce issues are one of the biggest challenges to improving the quality of care at these facilities. There are a shrinking number of workers willing to do this type of work while, at the same time, the demand for these services is growing. Poor wages, stress, burnout, and lack of benefits top the list of what must be tackled. "The jobs are lousy," Dawson said. "We are really asking people to work at more difficult jobs, less safe jobs, for less money than they can get elsewhere."

There is a dire need to pay more attention to the working conditions, training, and wages of these workers, Dawson continued. "If the caregiver is poorly trained, is new to the job, is a temporary worker, is worried about paying her own bills, is late because her car broke down or she doesn't have child care this morning, or is working short because her co-worker didn't show up, clearly, the quality of care your loved one is going to receive is going to be affected," he said.

Training of health care paraprofessionals is limited, and tends to vary across states and providers. Federal regulations require that nursing home and home care aides working in Medicare and Medicaid-certified organizations receive a minimum of only 75 hours of training. To improve the quality of care delivered by paraprofessionals, the IOM's Committee on the Adequacy of Nurse Staffing in Hospitals and Nursing Homes recommended that training for nurses' aides be expanded to include

## THE PLIGHT OF THE PARAPROFESSIONAL

Eight out of every ten hours of patient care in a long-term setting is provided by paraprofessionals such as home health aides, certified nurses' assistants (CNAs), and personal care attendants. Yet these are often the lowest-paid, most underappreciated, and highest-burnout jobs in health care.

"The quality of care that your loved one receives is going to be affected by the quality of the worker and the quality of the job that worker has," said Steven L. Dawson, president of the Paraprofessional Healthcare Institute, a national nonprofit health care employment development and advocacy organization in the South Bronx.

At one time, there was a seemingly never-ending pool of people willing to take these jobs. But with the improvement of the economy, 40 states have reported shortages of direct care workers, with turnover in some nursing homes reaching between 70 percent and 100 percent annually.

A crucial step in improving the country's long-term care system is improving the jobs and working conditions of these paraprofessionals. "I think we have to remember that there is a labor market out there and that people are now beginning to have a choice about what types of jobs are available to them. Right now – and it's been true for the last two decades – the quality of these jobs is extremely poor," Dawson said.

How poor?

The state of New Hampshire, in an attempt to better understand what steps to take to improve its long-term care system, convened focus groups of 50 CNAs, who revealed some interesting aspects of their job. Karen Hicks, policy director, New Hampshire Department of Health and Human Services, described key findings and observations:

- Working conditions are terrible. Many paraprofessionals work in understaffed facilities. One woman told of working in a nursing home that continued to place the name of another worker on the schedule long after that worker had quit.
- CNAs feel as if they have little decisionmaking responsibilities and must follow set routines, even if those routines are not in the resident's best interest. In addition, there are often cultural differences between these workers and the patients, adding to an already-strained, stressful situation.
- Wages and benefits are paramount.

These types of jobs must improve, Dawson and Hicks said, if long-term care facilities are to improve their quality of care.

States are starting to pay attention to the problem. In New Hampshire, the state legislature is considering wage pass-throughs that allocate reimbursements for direct-care services. Other legislation under consideration is the development of career ladders to create levels of expertise for CNAs, with master CNAs providing training to others, skill portability that allows workers in similar areas to take their credentials from job to job, and better management training for registered nurses who supervise these workers.

"We can't recruit our way out of solving the problem. We have to put our minds to making these jobs better," Hicks said.

And making the jobs better means that the quality of care delivered will be better as well.

*To be a dog groomer in Maryland, you have to have 1,000 hours' training; to be a manicurist, you have to have 300. So actually, in most states, you're better off as a poodle than you are as a nursing home resident.*

CATHERINE HAWES,
PROFESSOR,
TEXAS A&M UNIVERSITY,
JUNE 2000

*People can go to McDonald's and make $2 an hour more than they they're making in a nursing home or in a home health setting, and it's much easier work.*

KAREN HICKS, NEW HAMPSHIRE DEPARTMENT OF HEALTH AND HUMAN SERVICES, JUNE 2000

instruction on appropriate clinical care for the elderly, providing culturally sensitive care, and managing conflict within a stressful work environment (Wunderlich et al. 1996).

Staff retention is also important for improving quality. Paraprofessionals have traditionally suffered from low wages and benefits, two critical components of staff retention. In fact, the average hourly wage for nurses' aides is just $7.46 – in effect, minimum wage because the average workweek is just 20 to 25 hours (Stone 2000). More than 600,000 direct care workers go home to families who are living in poverty. In addition, and ironically, only about 30 percent of these workers have health insurance. Paraprofessionals are also at risk for work-related injury and emotional stress. Certified nurses' assistants (CNAs), for instance, have the third-highest injury rate of all occupations in the country. These and other factors have resulted in extremely high staff turnover rates, making it difficult for long-term care organizations to maintain quality services. The U.S. Department of Health and Human Services (HHS) estimates an annual turnover rate of between 70 percent to 100 percent in nursing homes and between 40 percent and 60 percent for home health care agencies (Wilner 1999).

Compounding the high turnover rate of paraprofessional health care workers is the expected shortage of such workers in the future. By about 2010, when the baby boom generation begins to need long-term care services, nursing homes will need 600,000 new nurses' aides (National Conference of State Legislatures 2000). "We built this system of care when labor was really plentiful," Dawson said, "and now we just have to recognize that that's not going to work anymore. We have to redesign the system based on the fact that labor is a scarce resource."

But there is some good news in all of this. "This workforce has been so ignored for so long that there's a number of things we can do to start paying attention to them," Dawson said. What is needed is for government, researchers, and grantmakers to look at ways to innovate these jobs. Many states have already implemented initiatives to improve long-term care quality by addressing the needs of paraprofessional health care workers. For example, although the federal government maintains staffing standards for RNs and licensed practical nurses (LPNs) in nursing homes, it does not set standards for nurses' aides. Federal regulations require that a nursing home have an RN on duty eight hours per day and an LPN on duty 24 hours a day. According to the National Conference of State Legislatures, 35 states go beyond the federal staffing standards by setting ratios for nurses' aides or hours of care per nursing home resident. Four of these states set ratios of nurses' aides to residents at 1:5 during the day, 1:10 during the evening, and 1:15 at night, with a minimum of 4.13 hours of direct nursing care per resident per day (National Conference of State Legislatures 2000).

States have also sought to improve quality by raising the hourly wages for paraprofessional health care workers. To date, 16 states have adopted wage pass-through laws that raise Medicaid payments for long-term care providers. All or some of the increase is then earmarked for the increase of wages and benefits for paraprofessional workers. For example, the Massachusetts legislature mandated a 5 percent wage pass-though in 1999 (National Conference of State Legislatures 2000). In addition, some states are considering making these paraprofessionals state employees in order to give them more benefits. Minnesota is studying this model as a way to extend health care insurance to nursing home employees. Rhode Island has expanded its Medicaid program to include in-home child-care providers.

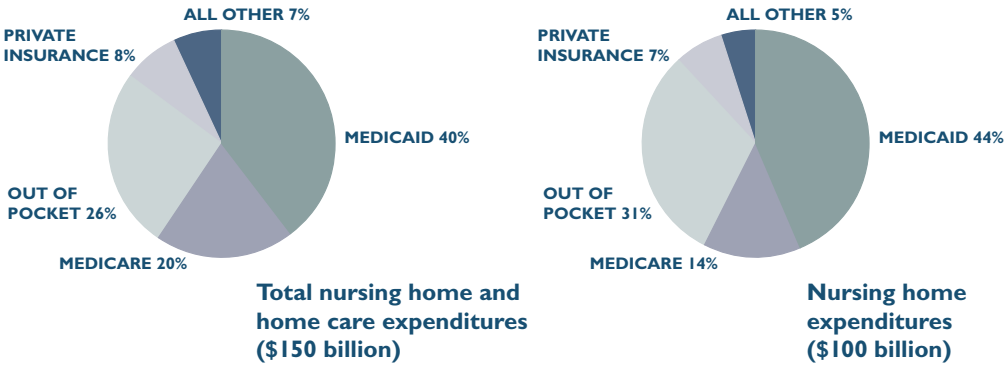
Foundations concerned with the workforce and poverty have begun to tackle this issue, most prominently The Ford Foundation, The F.B. Heron Foundation, The Kresge Foundation, the Charles Stewart Mott Foundation, and The Pew Charitable Trusts. Labor unions have also taken up the call, and are aggressively organizing direct care workers. A particular challenge in all of this, however, will be bringing together the stakeholders – consumers, labor, and providers – to work toward mutually beneficial goals rather than to fight over the pie.

## Paying for Long-Term Care

The substantial long-term care expenses of the elderly are financed from a variety of sources, including Medicaid, Medicare, out-of-pocket, and private long-term care insurance. Since 1980, spending for long-term care services increased approximately 12 percent per year, growing from $20 billion in 1980 to $98.5 billion in 1994 (Komisar et al. 1996). By 1997, a total of more than $115 billion was spent on long-term care in the United States, according to the Kaiser Commission on the Future of Medicaid and the Uninsured (Niefeld et al. 1999). Yet a significant portion of the actual cost of providing long-term care is not even reflected in these figures because of the difficulty of assigning a true value to the amount of services provided to the elderly by families and friends (Figure 3).

Nursing home residents are among the most financially vulnerable elderly, with about two-thirds of individuals having annual household incomes below $20,000 (Komisar et al. 1996). The average annual cost of nursing home care, however, is approximately $41,000 (American Health Care Association 1998). Because of its high cost, many elderly residents with nursing home stays exceeding one year (about 70 percent) have catastrophic long-term care costs – costs exceeding 40 percent of their total income and non-housing assets (Niefeld et al. 1999). As a result, the typical nursing home resident is, essentially, financially unable to meet the costs of care and will rely on Medicaid, the joint federal/state health care program for the poor. "When you go into that nursing home, even if

**Figure 3.** *Nursing Home and Home Care Expenditures, 1998*




Nursing home care is financed through a variety of sources, including public and private insurance and out-of-pocket. Together, Medicaid and out-of-pocket comprised 75 percent of total nursing home expenditures in 1998, with Medicare and private insurance comprising 14 percent and 7 percent, respectively.

Source: Feder, Judith, Harriet L. Komisar, and Marlene Niefeld, "Long-Term Care in the United States: An Overview," *Health Affairs* 19(3): 40-56, May/June 2000.

you are at that higher level of income, you give up everything," Feder said. "You get the service but you contribute everything towards it."

Many elderly, especially nursing home residents, must pay for long-term care services out-of-pocket. Estimates place out-of-pocket spending as a share of average annual income by nursing home residents aged 65 to 84 at about 30 percent of income, and at about 44 percent for residents age 85 and over (Friedland and Summer 1999). The increase in out-of-pocket spending for residents 85 and older reflects the longer nursing home stays of older residents (Komisar et al. 1996). Furthermore, saving for nursing home care is usually not a viable option. According to Hawes, any long-term care savings are frequently depleted when one spouse requires nursing home care, leaving the surviving partner without a source of private funding.

Of the two major health care programs in the United States, Medicaid finances the majority of long-term care. In 1997, Medicaid spending covered almost 40 percent of all long-term care expenditures, including half the costs of nursing home care (Niefeld et al. 1999). By 2018, Medicaid long-term care expenditures are expected to more than double because of the aging of the population and price increases due to general inflation (Wiener and Stevenson 1998a).

Because Medicaid is a joint federal/state program, there is considerable variation in the level of payments across states. The average national Medicaid expenditure on long-term care for the elderly was $7,821 in 1995. Payments ranged, however, from a high of more than $15,000 in Connecticut, the District of Columbia, and New York, to a low of $5,000 in Mississippi, Oklahoma, and South Carolina (Niefeld et al. 1999). The amount of long-term care spending committed to nursing homes also varies across states. According to Manard and Feder (1998), 20 states commit at least 60 percent of long-term care spending to nursing homes, while other states commit about 50 percent. And although federal law requires states to cover home health services for nursing home-eligible individuals, less than 20 percent of Medicaid long-term care spending nationally was for home- and community-based services.

Although Medicare is the nation's health care program for those over age 65, it finances only a small portion of long-term care services. Of the $115 billion spent on long-term care in 1997, only 20 percent was financed by Medicare, compared to 66 percent financed by Medicaid and out-of-pocket spending, and 14 percent financed by private insurance or other payers (Niefeld et al. 1999).

Medicare covers short-term, skilled nursing facility care, and limited home health and community-based care. These services are generally designed to meet an elderly patient's post-acute care needs. Changes to the Medicare program in the 1980s resulted in an increased use of the Medicare home health benefit by the elderly; however, even with this expansion, only a small portion of those in need of long-term care received services financed by Medicare (Niefeld et al. 1999). More recent changes to the Medicare program sought to constrain this increased growth. Bishop's (1999) analysis of National Nursing Home Survey data found that, in 1995, substantially more nursing home beds were occupied by residents receiving Medicare-financed post-acute care. Since Medicare finances only limited nursing home care, specifically post-acute skilled nursing care, patients receiving Medicare-financed care tend not to be permanent nursing home residents, but return to the community.

Private insurance plays a small role in the financing of long-term care services for the

elderly in part because persons who purchased this product when it first appeared are just now beginning to use it. One analysis estimated that, in 1995, private insurance covered less than 6 percent of nursing home and home health care costs (Stone 1998). Although the number of private, long-term care insurance policies has grown in recent years, only about 7 percent of the elderly own policies that explicitly cover long-term care services (Niefeld et al. 1999). A major obstacle to acquiring private long-term care insurance is price. The average annual cost for a policy covering four years of nursing home care and home care in 1996 was $1,200 if purchased at age 50, $2,432 if purchased at age 65, and $7,440 if purchased at age 75 (Stone 1998). Typically, these policies have been affordable only to middle- and upper-income elderly, leaving lower-income elderly (often those most in need of long-term care services) to rely on a combination of their own resources, Medicaid, and Medicare.

Our system of financing long-term care places the greatest financial burden on the near poor. Even though billions of dollars are spent on long-term health care in this country, many needs remain unmet. About one in five in this population report forgoing needed care, which can affect their ability to eat, toilet, and perform other functions. Hawes says the poor can rely on Medicaid, and those with some money can supplement home care service. But the near poor, with incomes at 125 percent to 250 percent of the federal poverty level, have neither option. This situation will only worsen if no policy changes are made. "If we're not going to take care of everybody," Feder said, "then direct some public resources toward an adequate system for the low- and modest-income population."

# Public Policies and Regulation:
## Shaping Long-Term Care Payment, Provision, and Quality

The primary federal policies influencing long-term care are the Social Security Act, the Omnibus Reconciliation Act of 1987 (OBRA-87), the Balanced Budget Act of 1997 (BBA), and the Older Americans Act. Each of these pieces of legislation has contributed to shaping the provision of long-term care services and improving the quality of patient life. The Social Security Act and the BBA focus on the financial aspects of long-term care, specifically payments to providers participating in the Medicare and Medicaid programs. Patient quality of life and nursing home resident advocacy are emphasized in the Older Americans Act, which established the nationwide Long-Term Care Ombudsman Program. In contrast, OBRA-87 addresses the regulation and inspection of nursing homes. This section presents a brief description of the major legislative programs focused on the quality of long-term care services, especially in nursing homes.

### The Social Security Act

In the past, federal payments for nursing home care were made under the Old Age Assistance and Medical Assistance for the Aged program. At that time, there were no federal standards governing the nursing home industry other than requiring that nursing homes receiving such payments be licensed by the state in which they operated (Hawes 1996). The advent of the Medicare and Medicaid programs introduced long-term care standards intended to protect both the welfare of nursing home residents and to ensure that federal funds were spent solely on nursing homes meeting basic criteria for

safety and quality. These standards were unable, however, to ensure quality services, and reports of poor quality continued. As a result of the lack of oversight, nursing home conditions and quality varied widely across states, leading to state and federal concern for and interest in the quality of care provided to residents. In the mid- to late-1950s, a number of reports documented widespread quality problems. For example, a 1955 Council of State Governments report found that the majority of nursing home staff were untrained and that most homes provided low quality care to residents (Hawes 1996).

## Omnibus Budget Reconciliation Act of 1987

In response to the failure of the federal standards enacted in the Social Security Act and continued concerns for the quality of care delivered in nursing homes, the U.S. Congress sought to introduce policy designed to significantly improve the quality of long-term care. This policy, contained in OBRA-87, set forth comprehensive reforms aimed at addressing major quality deficiencies identified in more than 30 federal and state reports issued in the 1970s and 1980s. Coupled with hearings held by the U.S. Congress and the IOM's Committee on Nursing Home Regulation, these reports revealed substandard nursing home care and ineffective regulation of nursing home quality.

OBRA-87 changed the standards that nursing homes must meet in order to participate in the Medicare and Medicaid programs. As described earlier in this section, prior to OBRA-87, federal standards focused on nursing homes' ability to provide care, not on the quality of care received by residents (GAO 1999a). OBRA-87 refocused federal standards on the actual delivery of care and the results of that care by centering on three main areas: good standards, inspections to determine if the standards are being met, and compliance mechanisms for when they are not.

As described by Hawes (1996), OBRA-87 addressed several key components of nursing home regulation. First, it addressed the primary deficiencies of the previous regulatory system by altering the standards, determining nursing home compliance using survey and surveillance systems, and creating an enforcement system for non-compliant nursing homes. Second, the OBRA-87 reforms were designed to be resident focused and outcome oriented by emphasizing the process of care provided and requiring that care promote "maximum practicable functioning." This was achieved by giving equal regulatory importance to the provision of quality care, the quality of life, and to the rights of nursing home residents. For example, the modified inspection process included interviews with residents, family members, and ombudsmen about their daily experiences, along with direct observation of residents and the care they received. These unannounced inspections did not occur at predictable times. Finally, the reforms incorporated a range of successful state enforcement sanctions for encouraging nursing home compliance. These sanctions were designed to match the severity of the nursing homes' deficiencies, depending upon the circumstances and actual or potential harm to residents.

Since implementation of the OBRA-87 reforms, researchers have documented improvements in nursing home care practices and resident outcomes. One important study conducted by the Research Triangle Institute (RTI), and funded by the Health Care Financing Administration (HCFA), revealed an increase in the comprehensiveness of care planning to address a larger portion of each resident's health problems and functional status, as well as improvements in practices that affect

both the quality of care and quality of life, such as increased family and resident involvement in care planning, increased use of hearing aids, and increased use of behavioral management programs (Hawes 1996). The RTI research also revealed a decline in disturbing practices, including use of in-dwelling catheters and physical restraints.

## Regulatory Environment for Long-Term Care Providers

Together, the Social Security Act and OBRA-87 established federal policy governing long-term care quality. These pieces of legislation sought to address many aspects of quality, including service delivery, quality standards, and payments to providers participating in the Medicare and Medicaid programs. As a result, nursing homes today operate in a highly regulated environment, with emphasis on the quality of services provided, as well as the quality of patient life. Compared to nursing homes, however, there is considerably less oversight of home health care, assisted living, and other long-term care providers.

The federal government and states share responsibility for oversight of long-term care services. At the federal level, HCFA is responsible for setting quality standards for nursing homes participating in the Medicare and Medicaid programs. HCFA requires state agencies to survey these nursing homes at least once every 15 months, and shares responsibility with states for enforcement activities to ensure that deficiencies identified during surveys are corrected (GAO 1999b). Compliance with licensing requirements is checked during these standard surveys. If a Medicare-certified nursing home is found to have deficiencies, or when a home fails to correct deficiencies, the state must refer the case to HCFA with recommendations for sanctions. HCFA holds the authority to impose sanctions and collect any monetary penalties (HHS 1999).

Recent research conducted by the U.S. General Accounting Office (GAO) (1999b) at the request of the Senate Special Committee on Aging revealed that "while HCFA has taken steps to improve oversight of nursing home care, it has not yet realized a main goal of its enforcement process – to help ensure that homes maintain compliance with federal health care standards." According to the GAO's report, more than one-quarter of the 17,000 nursing homes in the United States had deficiencies that resulted in actual harm to residents or placed them at risk of injury or death. The most frequent violations included inadequate prevention of pressure sores, failure to prevent accidents, and failure to assess residents' needs and provide appropriate care. Furthermore, although the majority of nursing homes corrected these problems, subsequent surveys revealed that the problems often returned. Approximately 40 percent of the nursing homes found to have deficiencies in 1995 had the same problems again in October 1998.

Although the federal government has the authority to initiate sanctions against noncompliant nursing homes, the GAO's research found that, in most cases, sanctions were never implemented. The report suggests that fines and other penalties are potentially strong deterrents because they can be applied even if a nursing home comes back into compliance. The GAO concludes, however, that the usefulness of such penalties is hampered by a backlog of administrative appeals and legal provisions that prevent the collection of penalties until the appeals are resolved.

In some cases, the collection of sanctions has been delayed for several years. Cynthia Graunke, director of HCFA's division of nursing home and continuing care services, estimates that only $4 million to $5 million in fines have been collected from nursing homes since the regulations went into effect in 1995.

In addition, because of a backlog of appeals and a scarcity of administrative judges to hear them, nursing homes that "want their day in court" can delay the collection of fines or compliance with ordered corrections for years. Finally, the GAO's report identified several additional issues that need to be addressed by HCFA in order to improve oversight of nursing homes, including strengthening the use of civil monetary penalties, improving the state referral process for sanctions, and increasing the deterrent effect of terminating homes from the Medicare and Medicaid programs.

## Balanced Budget Act of 1997

The Balanced Budget Act (BBA) altered payments for long-term care services under Medicare and Medicaid. Payment changes are a large concern for long-term care providers and advocates. Although research has not determined a specific level of payment necessary to provide adequate quality care, quality concerns have been the traditional catalyst driving federal standards for nursing home payments (Manard and Feder 1998). Another potential consequence of payment reductions is reduced access to nursing homes or other long-term care providers, particularly for elderly in need of more intensive services, and therefore more costly care (Manard and Feder 1998).

The BBA required that Medicare's skilled nursing facility payment system convert to a prospective payment system based on facilities' patient case mix rather than being based on historical costs (with some adjustments and limitations) (MedPAC 1998). Using patient classification systems, the new system is designed to reduce the overall level of federal spending on nursing homes, to more accurately reflect the cost of patient care, and to provide a financial incentive for more efficient care management (Vladeck 1998). The BBA also requires nursing homes to take full responsibility for all Medicare billing, except for physicians' services. This provision may modestly increase the administrative burden on nursing homes and, more significantly, may require homes to renegotiate their relationships with diagnostic and therapeutic service providers (Vladeck 1998).

The BBA also attempted to respond to the escalating costs of home health care services, as well as fraud and abuse, and concerns about substandard home health providers. In order to control costs, for example, the BBA required the development of a prospective payment system, similar to the one required for nursing homes. While this new system is under development, HCFA adopted a stringent interim payment system, which has already reduced payments to home health care agencies. HCFA also implemented a series of legal and regulatory changes to further refine the definition of the Medicare home health care benefit and prescribe higher standards for home health agencies (Vladeck 1998).

Lastly, the BBA altered Medicaid payments for long-term care by repealing the Boren Amendment and giving states more freedom in setting Medicaid nursing home payment rates. As a result, the federal government no longer sets minimum standards for Medicaid nursing home payments and permits states to determine how their rates are set (Manard and Feder 1998). Although the repeal of the Boren Amendment could have a significant financial impact on nursing homes receiving Medicaid payments, few states have sought significant Medicaid savings because of the strong economy and low growth rate in Medicaid expenditures (Wiener and Stevenson 1998b). As Manard and Feder (1998) note, the ultimate impact of the repeal will depend largely on whether states alter how their rates are set and how much nursing homes are paid.

## The Older Americans Act

One of the most successful long-term care quality improvement initiatives is the Long-Term Care Ombudsman Program. Initially begun in 1972 as a demonstration program, the U.S. Congress amended the Older Americans Act in 1978 in order to establish ombudsman programs in all 50 states. At the federal level, the program is administered by the Administration on Aging (AOA), and each state maintains an office of the long-term care ombudsman, generally housed within the state unit on aging.

The AOA describes ombudsmen as advocates for residents of nursing homes, board and care homes, assisted living facilities, and other adult care facilities. Ombudsmen regularly visit nursing homes and other facilities in order to monitor conditions and care, and are responsible for resolving individual resident problems and conveying the need for change to local, state, and national agencies. In 1998, there were more than 900 paid ombudsmen and 7,000 certified volunteer ombudsmen. They investigated 200,000 complaints made by 121,000 individuals. They also provided information on long-term care to another 200,000 people (AOA 2000).

In a 1992 congressionally mandated review of the long-term care ombudsman program, the IOM (1994) concluded that the program contributed to improving the quality of nursing home and other residential care facilities through advocacy work and educational efforts. The report asserts that "the state programs have brought to the attention of state and federal policymakers, regulatory agencies, and provider organizations a host of conditions that can be changed to improve the health, safety, rights, and welfare of residents." For example, ombudsman programs have contributed significantly to reduced use of physical restraints, improved building and safety standards, increased funding for inspections and surveys of facilities, and better licensing and oversight of health care professionals providing long-term care services.

The IOM also found, however, that although some states vigorously implemented ombudsman programs, many had not been implemented with regard to an important provision contained in the Older Americans Act: that ombudsman services be available and accessible to all residents. Additionally, the IOM determined that ombudsman programs might face inherent conflicts of interest. Specifically, the physical location of the offices of state long-term care ombudsman programs and the political environment in which ombudsmen work may add to the potential for conflict. Furthermore, ombudsmen are to act as advocates and speak out against policies and regulations when warranted, yet they typically are state employees.

## THE WELLSPRING MODEL: RESEARCH APPLIED

To determine whether quality improvement measures in practice in one place can be replicated successfully elsewhere, The Commonwealth Fund is supporting the evaluation of a promising consortium of long-term care facilities.

Wellspring Innovation Solutions, Inc. is an alliance of 11 nursing homes in Wisconsin that first joined forces in 1994 to better position and market themselves for managed care. Other benefits derived from the consortium soon proved more successful, however, such as increased purchasing power and quality improvement efforts.

A team of researchers has embarked on a vigorous evaluation of the program, with the hope of identifying the unique factors of quality improvement measures utilized throughout the Wellspring model. Robyn I. Stone, the research team's co-principal investigator and executive director of the Institute for the Future of Aging Services at the American Association of Homes and Services for the Aging, described Wellspring and the research project at the Issue Dialogue. "We want as rigorous an evaluation as possible to identify what works and what doesn't work, and to set the stage for replication," Stone said.

This is how Wellspring works. Chief executive officers from each of the 11 facilities contribute $2,000 a month to the effort and meet formally every month. Together they have hired a geriatric nurse practitioner who spearheads clinical and management training and other activities.

The linchpin in the success of Wellspring is the empowerment of certified nurses' assistants (CNAs). They track patients' progress and have become an integral part of the care-delivery team, almost to the point of becoming amateur epidemiologists. Some CNAs also have purchasing authority and make their own schedules.

"The CNAs have become empowered to use data, to look at what they are doing and what happens to the folks that they are working with," Stone said. "It is a focus on clinical practice, good clinical practice. Make the CNA a significant partner in all of that and it's not just telling them what's happening. They own the stuff they do," she said.

In addition, the CNAs form partnerships with colleagues in the other Wellspring facilities so that they can compare notes and consult with each other. If, for instance, they are having trouble with patients falling, they can call their "buddy" to find out what the other facility is doing and if it works better.

The nurse practitioner conducts two-day training sessions around clinical modules. At these sessions, various employees across the board participate, drawn from all 11 facilities. Nurse practitioners are then responsible for implementation at their site with the help of nurse coordinators, who serve as liaisons and troubleshooters.

But the extensive decisionmaking power given to the CNAs is not without problems. A significant roadblock in this new system is that the nursing staff, particularly middle managers, have had trouble giving up responsibility to the CNAs, to the point where Wellspring has experienced serious turnover in nursing staff. "One problem that they've had so far is getting the directors of nursing to buy into this," Stone said. "It's an issue of training and proclivity. And that's culture change, and those things don't happen overnight," she said.

The evaluation of Wellspring will compare both quantitative and qualitative activity. The team will evaluate residents' health and functioning, their satisfaction and that of their families, and the quality of work life for the staff. The evaluation will also analyze the costs of providing this high level of care.

Much of this analysis will benefit from the wealth of data already collected by Wellspring, which is compared quarterly among consortium partners so they can benchmark how they are doing in such areas as falls, urinary incontinence, depression, and other potential problems found in nursing homes.

The state of Wisconsin has much data to be used in the evaluation. In the project, researchers will develop a synthetic treatment control group. Some of the planned analysis includes review of selected quality indicators, staff retention, satisfaction, and turnover.

The evaluation – which will include observations, focus groups, and site visits at the Wellspring consortia – will take a year to complete. Stone hopes the project is a way to bring together the research, practice, and policy communities.

"The potential contribution of this is to significantly affect the nature and scope of quality activity in long-term care, to look at strategies, best practices, and specific tools that could be further disseminated," she said. "The reality is that best practices are great but they don't mean very much unless we really know that they make a difference."

# Grantmaker Activities:
## Improving Quality for Elderly with Long-Term Care Needs

Grantmakers have adopted a number of ways to improve the quality of long-term care around the country. Some of these approaches include evaluations of current programs with the aim of replication, development of innovative programs that address a particular segment of the long-term care population, and improving communications through guides, videos, and in some cases, the Internet. Grantmakers can also influence quality of long-term care by supporting the private sector, government, and consumer groups in their efforts to measure, monitor, and address identified problems. This section highlights examples of work by several foundations in this arena.

### The Commonwealth Fund

The Picker/Commonwealth Program on Long-Term Care for Frail Elders, begun in 1993, focuses on the evolving long-term care needs of the elderly and strategies to meet those needs. The program seeks to promote sound public policy to ensure that long-term care will be affordable for all elderly and will enable them to live with dignity and comfort. Its objectives include gathering and disseminating information on the quality of long-term care services, tracking states' responses to increased flexibility in long-term care financing under Medicaid, and studying efforts to integrate acute and long-term care services.

To meet these objectives, the Fund has sponsored numerous activities and research initiatives, as follows.

- *Evaluation of the Wellspring Program as a Model for Promoting Quality of Care in Nursing Homes:* A one-year, $368,046 grant to the American Association of Homes and Services for the Aging to evaluate the effectiveness of the Wellspring Program. Developed by an alliance of 11 nursing homes in eastern Wisconsin, the program is based on the philosophy that nursing home management sets quality-of-care policies and that frontline workers – those who know the residents best – decide how to best implement these policies.
- *Program Direction and Policy Analysis for the Picker/Commonwealth Program on Long-Term Care:* A $374,822 grant to Georgetown University to analyze the use of home health care by the chronically ill, review the impact of nursing home costs on the financial well-being of the elderly, and assess the baby boom generation's need for long-term care and the future availability of care.
- *Effects of the 1987 Omnibus Budget Reconciliation Act Nursing Home Reforms on Quality:* A $24,854 grant to the Menorah Park Center for Aging to support an analysis of the OBRA-87 nursing home reforms a decade after their implementation. It builds upon a previous analysis of the history and impact of the federal standards contained in OBRA-87.
- *Assessing and Improving Nursing Home Quality of Care:* A $149,764 grant over 15 months to the University of Wisconsin to support an analysis of the relationship between indicators of quality of care, and the characteristics of nursing homes and residents. This research could begin to produce easily understood aggregate measures of quality of care.
- *Supporting State Nursing Home Quality Assurance Efforts:* A $201,147 grant over 16 months to the National Academy for State Health Policy to identify state quality assurance strategies for nursing homes and to pro-

vide up to five states with technical assistance to improve their enforcement programs.

The Fund's program has also produced a number of Issue Briefs focused on a diverse range of long-term care issues. These topics include access to health care for elderly people as the baby boom generation ages, innovative long-term care programs in New York, analysis of federal legislation to improve access to health care services, and the potential impact of economic and demographic factors on long-term care in the United States

## Archstone Foundation

The Archstone Foundation's mission is to contribute to the preparation of society in meeting the needs of an aging population. In 1995, the foundation refined its focus from the full spectrum of health to one directed exclusively toward challenges in the later stages of life, such as maintaining independence at home, improving the quality of care in institutional settings, and improving care at the end of life. Examples of three recent Archstone grants are presented below.

- *Management Training in Long-Term Care:* A five-year, $1 million grant to the California State University at Long Beach's Center for Health Care Innovation. The grant will be used to develop a master's curriculum and certificate program for professionals working within the continuum of long-term care service and policy.
- *Elder Abuse Prevention:* A two-year, $96,386 grant to the National Center for the Prevention of Elder Abuse to provide training and technical assistance to cross-agency teams around the county. Working in their local communities, the teams prevent and intervene in financial abuse and exploitation of the elderly by bringing together members of law enforcement, adult protective services, the judicial system, the banking industry,

## THE INTERNET: A GROWING SOURCE OF QUALITY INFORMATION FOR CONSUMERS

The Hulda B. and Maurice L. Rothschild Foundation recently commissioned a local better government bureau to build a Web site for Chicago consumers, listing all documented information on area nursing homes. In addition, a team will be sent out to complete site visits with findings posted on the Web site. Consumers will also find a chat room to discuss their own experiences with particular facilities.

The California HealthCare Foundation hopes to create a similar Web site for California nursing home consumers and has funded three universities, a think tank, and a consumer group to be part of the project. The Web site should be up in two years.

In addition, the federal government is working on its own long-term care Web sites. The Health Care Financing Administration (HCFA) is among several organizations that are posting information about the quality of nursing homes on the Internet, with more under development in the next few years. HCFA's popular Web site, www.medicare.gov, lists every nursing home in the country with the last survey conducted at each, as well as the scope and severity of deficiencies found and the conditions of residents. Recent additions include staffing levels of various workers in the homes. The site also has links to resources to help consumers select a nursing home.

elderly service providers, and the health care community.

- *Ombudsman for Long-Term Care:* A $2,000 grant to the ombudsman for long-term care in California for the recruitment and training of volunteer ombudsmen. The ombudsman program provides ongoing training for volunteers who visit residents, investigate complaints and abuses, and assure a higher quality of life for elderly residing in long-term care institutions.

## California HealthCare Foundation

A relatively new foundation, the California HealthCare Foundation focuses on critical challenges confronting a changing health care marketplace such as managed care, California's uninsured, the state's health policy and regulations, and quality of care. The foundation awards grants to proposals that can initiate meaningful research, policy recommendations, and innovative programs.

One such program is the new California Nursing Home Consumer Information System that will give Californians objective, unbiased, and easy-to-understand ratings of the quality of care found in California's nursing homes. To develop the system, the California HealthCare Foundation has awarded $2.4 million in funding to a coalition of the University of California at San Francisco; the University of Wisconsin, Madison; RAND; the UCLA/Borun Center for Gerontological Research; and the California Advocates for Nursing Home Reform. Researchers will design two sets of indicators: one that focuses on the facilities, such as appearance, complaints filed, staff levels, and turnover rates; and another that focuses on quality of care, such as eating, psychotropic drug use, accidents, and behavioral and emotional patterns. The information will be posted on a Web site, and foundation officials hope that it will become a model program for other states and the federal government.

## The Flinn Foundation

The Flinn Foundation's work strives to increase access to quality health care for Arizona's citizens by providing useful, objective data to enhance informed decisionmaking in health care. With respect to long-term care, the foundation funded a model program to demonstrate new ways to care for Alzheimer's patients, especially how to help these patients remain as independent as possible. Prevention, early intervention for medical and emotional problems, family and caregiver support, low use of medications, ample staffing and training are key components of the model. An evaluation of the demonstration found that the 13 assisted living facilities participating in the project were providing safe, high quality, and cost-effective care. The success of this program has enabled Arizona to become the first state to license a new model of long-term care for Alzheimer's patients.

## The Henry J. Kaiser Family Foundation

The Kaiser Family Foundation works extensively on issues pertaining to the elderly. Two recent projects funded by the foundation address the quality of long-term care.

- *Profiling the Cost of Long-Term Care for Patients and Families:* This grant to The Manard Company will document the cost of long-term care services borne by private paying patients, and will demonstrate how patient payments vary by payer, type of service, provider, and location.
- *Examining Medicaid's Role in Nursing Home Care:* This grant to the University of California, San Francisco, supports the examination of Medicaid's role in providing nursing home care, and features two companion, 50-state surveys. The first, on state licensure and certification agencies, examines how states conduct nursing home surveys, the nature of the problems uncovered and how they have

changed, what actions are being taken when problems are identified, and the resources dedicated to carry out surveys and certification in each state. The second survey is on state ombudsman programs and will examine quality issues from the perspective of patient advocates, including whether ombudsman responsibilities vary from state to state, the nature of complaints received, and ombudsman funding levels.

## Milbank Memorial Fund

Between 1997 and 1999, the Milbank Memorial Fund and the American Association of Homes and Services for the Aging convened trustees and executives of nonprofit and investor-owned long-term care organizations to discuss future policy in institutional long-term care. The resulting report, *Long-Term Care for The Elderly with Disabilities: Current Policy, Emerging Trends, and Implications for the Twenty-First Century*, examines three important questions about long-term care for the increasing number of frail elderly in the United States: who should pay for long-term care services and through what mechanism; how to design and deliver these services; and how to recruit, train, and retrain a workforce to deliver long-term care services.

In partnership with the Aging and Health Program of the World Health Organization, the Fund developed the International Long-Term Care Initiative, focusing on the concerns of older persons around the world in need of long-term care. The initiative encourages regional and international cooperation to secure older persons' independence, participation, care, self-fulfillment, and dignity. The joint initiative addresses two primary areas of concern: the importance of arrangements for continued lifelong development, and the sustenance and care of older persons who require long-term care.

## The Retirement Research Foundation

The Retirement Research Foundation's work is dedicated to aging and retirement problems, and supports innovative projects which develop and/or demonstrate new approaches to the problems of older Americans and have the potential for national or regional impact. Specifically, the foundation supports programs that: improve and increase the effectiveness and ability of community programs to maintain older adults in independent living environments; improve the quality of nursing home care; offer new and expanded employment and volunteer opportunities for older persons; and support selected basic, applied, and policy research that seeks solutions to significant problems of the aged.

Examples of recent Retirement Research Foundation grants include:

- *Study of Use of Hospice in Nursing Homes:* A two-year, $324,702 grant to researchers at Brown University to examine national data on the growth and current use of hospice in nursing homes. The study will also describe residents enrolled, conduct site visits, and assess the incremental value of providing hospice services in nursing homes.
- *Nursing Home Ombudsman Program:* A two-year, $408,554 grant to the Illinois Retired Teachers Association Foundation for a project to develop a nursing home ombudsman program model incorporating public-private partnerships.
- *Study of Malnutrition in Nursing Home Residents:* A $83,595 grant over 18 months to the University of Texas to study malnutrition and its clinical correlates in nursing home residents. The study will also seek to develop clinical interventions.

## THE FLINN FOUNDATION: ALZHEIMER'S PATIENTS FIND HOPE

In the early 1990s, finding appropriate long-term care for a growing number of Arizonans with Alzheimer's disease was becoming a crisis. In response, The Flinn Foundation embarked on a project to adapt a successful New Mexico model for the long-term care of Alzheimer's patients. The Phoenix-based foundation distributes about $8 million annually, with 75 percent going to projects which focus on increasing access to health care for vulnerable Arizonans.

The New Mexico model, The Casa Maria Alzheimer's Center in Albuquerque, focuses on prevention of illness and maintenance of skills through activities designed to meet the functional capabilities of dementia patients. The 45-bed program implements these patient care goals through caregiver education and support; a staff-to-patient ratio of one-to-six; daily nurse practitioner consultations; continuing education; and caregivers organized into continuous quality improvement groups. Staff also have access to subsidized adult and child daycare facilities, limited subsidized housing, group health benefits, a retirement program, crisis support, and education on how to manage their personal finances.

William Read, an associate director at The Flinn Foundation, described the Casa program: "On my first visit, I wondered why these people were in this center. It was an assisted living congregate care program," Read said, "treating the most difficult patients in long-term care. Yet the staff were happy, and the clients were having fun. I thought they were just putting this all on for my benefit. It turned out this was happening seven days a week."

The difficulty with persons with Alzheimer's disease, according to Read, is that they are, for the most part, physically healthy. Unlike traditional nursing home patients with multiple medical problems, Alzheimer's patients usually do not need skilled nursing care, though this is the setting where they most often end up. Behaviorally, however, they are hard to manage, and often are overmedicated and restrained, leading to medical problems, mental and emotional decline, and high care costs. By contrast, the goals of the Casa program are to minimize medication and maximize activities, preventing unnecessary hospitalization and emergency room visits, and maximizing and maintaining function. Casa's success with this approach has translated into daily fees that are lower than other settings, making care affordable for individuals from a broader socioeconomic range.

Could this model be adapted and rolled out in Arizona? Implementation issues included how to introduce a new model of care in a regulatory environment resistant to change; how to engage both nonprofit and for-profit providers; and how to market the model program to potential clients, as well as public and private payers. Additionally, if the program were to be successful, it had to be affordable, and cost less than traditional Medicaid skilled care.

Read met little resistance from his board of directors. "The attorneys on the board were trustees for individuals and families trying to cope with dementia. They had no programs to refer them to other than traditional nursing homes. The physicians on the board had patients with dementia, and they were equally frustrated in trying to help their patients and families cope," he said.

But the directors were concerned about two major issues: how to proceed, in view of the foundation's restrictions on funding for-profit organizations, and how best to stimulate official recognition of a new model by the state and its agencies.

The foundation resolved the problem of assisting for-profit providers by awarding a one-year grant to the nonprofit Phoenix Chapter of the Alzheimer's Disease Association to undertake a program of education and technical assistance for both nonprofit and for-profit long-term care providers. Simultaneously, the foundation supported the chapter in convening an advisory committee representing regulatory agencies, the governor's office, key legislators, advocacy organizations, and community leaders. Its purpose was to support providers by facilitating official state recognition of the new care model. The foundation set two performance goals to continue support for the project after the first year:

- at least one provider needed to formally commit to developing the program, and
- state leaders had to agree to seek Arizona legislative approval and a method for regulating the new model.

Seven long-term care providers, a mix of for-profits and nonprofits, agreed to participate and to finance the model program through their funds.

The foundation subsequently awarded a multiyear grant to the Phoenix Alzheimer's Chapter to continue the extensive technical assistance to providers and the advisory committee. Assistance included facility design, staff recruitment and training, marketing support, consultation to resolve implementation problems, recruitment of additional providers, and organization of medical oversight. Since the foundation provided no support for direct lobbying activities, the chapter used its own funds to work with the health committees of the state legislature.

In the second year of the program, the legislature passed legislation authorizing a three-year demonstration of the so-called Arizona model. If the legislature found the program credible and safe at the end of the demonstration, licensing standards would be enacted into law to formally recognize the new program.

To support the state legislature's demonstration, an additional grant was made to researchers at the University of Arizona in Tucson to evaluate the program. They found the program to be safe, with high quality care. Staff turnover was half the rate found in Arizona nursing homes and assisted living centers. Hospital and emergency room admissions were two-thirds less than that of other long-term care facilities, and family and staff satisfaction was much higher. At the end of the demonstration, the program was recognized in legislation and minimal licensing standards were approved. The Phoenix Alzheimer's Chapter then established a voluntary accreditation program, which included a higher set of standards than recognized in law.

Fourteen long-term care companies now participate and, collectively, have cared for more than 1,000 dementia patients. Additionally, three other states have copied the program, while others are considering adopting it. On average through seven years of program support, the foundation has spent approximately $50,000 per year, plus the $100,000 evaluation grant.

## The Hulda B. and Maurice L. Rothschild Foundation

The Rothschild Foundation's primary focus is on improving the quality of life for older adults in the Chicago area. Its three major components are:

- *Improving Environments:* This program is dedicated to integrating seniors and their families into the planning and design of senior facilities, including long-term care. For example, the foundation recently provided a $215,574 grant to the Picker Institute to define the elements which residents and families find contribute to patients' sense of independence and improve their quality of life.
- *Improving the Quality of Residential Care:* Recognizing that most skilled nursing facilities lack an organized and effective means for bringing the arts to their residents, this program contracts with a variety of performing artists, zoos, and museums to travel to nursing homes. Programs typically last 45-60 minutes, and are designed to include audience involvement and to reach out and engage seniors both verbally and physically.
- *Supporting Selected Basic, Applied, and Policy Research:* The foundation is currently supporting two initiatives in this area. The first is a two-year, $178,525 grant to the Better Government Association to create an interactive, Internet-based guide for Chicago-area long-term care facilities. The guide will serve as a resource for families and individuals seeking care, and will help them to locate, evaluate, and compare facilities. The second project is a one-year, $100,000 grant to the Metro Chicago Senior Foundation to create and staff a new organization to campaign for better public transportation for seniors.

## The Fan Fox and Leslie R. Samuels Foundation, Inc.

The Fan Fox and Leslie R. Samuels Foundation's health care program focuses principally on the issues and health care needs of the elderly. The foundation's work focuses on quality improvement, education and training, workforce development, consumer advocacy, communication, and ethics. The overarching aim, said Mary Jane Koren, vice president and director of healthcare programs at the foundation, is to direct research that in some way can "touch real people." In addition, the foundation has attempted to try to help develop long-term care systems other than nursing homes. Projects funded by the foundation to improve the quality of long-term care services and patient life include:

- *Advocating for Best Practices for Long-Term Care Problems:* A $181,000 grant over 36 months to Friends and Relatives of Institutionalized Aged, Inc. The objective is to find out whether families and other advocates of nursing home residents can become knowledgeable about solutions for common nursing home problems and then act as change agents and resources to help administrators adopt best practices to benefit residents.
- *Improving Communication about End-of-Life Care:* A two-year, $325,000 grant to Health Research, Inc. to improve communication between nursing home residents and staff about end-of-life issues. The project is led by the New York State Task Force on Life and the Law and is one component of a larger project funded by The Robert Wood Johnson Foundation.
- *A Consumer Guide to Nursing Homes:* A $20,000 grant to Friends and Relatives of Institutionalized Aged, Inc. to support the update and reprint of *Eldercare in the 90s*, a guide to nursing home selection in New York City.
- *Investigating Physical Restraints in Care for the Elderly:* A $47,000 grant to Mt. Sinai Medical Center to investigate the recollections of and effects on elderly intensive care unit patients who have been physically restrained,

and to explore the effect of administratively controlled and patient variables on the use of physical restraints in hospitals.

- *Developing an Instrument to Inventory Lifestyle Choices:* A $275,495 grant over 20 months to the Visiting Nurse Service of New York. This project is designed to examine at what point individuals entering nursing homes are no longer able to articulate what their personal habits and preferences are. The instrument could also be used with early dementia patients and their families to create an enduring record of the things patients like so that nursing staff may better personalize care.
- *Training Nurses Aides in Dementia Care:* A $20,000 grant to Cobble Hill Nursing Home for a training manual aimed at improving the dementia care skills of nurses' aides.

## United Hospital Fund of New York

The Fund's Nursing Home Initiative seeks to improve the quality of life of nursing home residents, to provide support to families seeking nursing home care, and to recognize nursing staff who provide hands-on care. To improve the quality of life for nursing home residents, the Fund has awarded 18 grants totaling $600,000. A sampling of these grants is presented below.

- *Bishop Henry B. Hucles Episcopal Nursing Home:* A $35,000 grant to provide residents with dementia who wake at night with therapeutic recreational activities to reduce restlessness, disorientation, and anxiety.
- *Center for Nursing and Rehabilitation:* A $30,000 grant to transform the institution's culture into one that is more home-like, giving residents greater control of their daily care and activities.
- *Daughters of Jacob Nursing Home:* A $35,000 grant to measure and assess the quality of resident-staff interactions and relationships, and to develop interventions to improve them.
- *Metropolitan Jewish Health System and Terence Cardinal Cooke Health Care Center:* A $60,000 grant to design and implement approaches to assure appropriate continuity of care for residents admitted or readmitted to these nursing homes from the hospital.

## Future Activities for Grantmakers

Grantmakers can contribute significantly toward improved long-term care quality for our citizens in a number of directions. Initiating research, advocating labor reforms, spurring consumer advocacy groups, creating pilot programs, developing public policy, and disseminating information are a few examples of the different pathways available. Even small amounts of money can go a long way toward creating some exciting programs. "An important role that foundations can play is promoting a variety of support mechanisms for long-term care patients and their families, and developing sources of impartial information," Feder said. Grantmakers at the Issue Dialogue warned, however, that this type of grantmaking work is very labor-intensive, interactive, and collaborative. Some grantmakers described the process as creating partnerships with grantees to make sure programs move forward and accomplish stated goals.

Research was mentioned several times as critical to improving the quality of long-term care. There has been little to no adequate research evaluating the effectiveness of nursing home regulations to determine what works, what is essential, and what are the best conditions under which a regulatory system functions. Research on staffing issues – including how to attract and retain good staff, and what levels of staff are needed to create an environment of quality care – is also meager. For example,

*If you probe in your communities, you will find creative activities going on in long-term care settings across the spectrum, from nursing homes to home- and community-based systems. There are opportunities waiting for you, I would say, in every community.*

ROBYN I. STONE,
AMERICAN ASSOCIATION
OF HOMES AND SERVICES
FOR THE AGING,
JUNE 2000

research projects could bring together labor experts and health care economists to come up with an agenda addressing the labor shortage and job conditions of paraprofessionals.

Also, little has been done to analyze the relationship between Medicaid payment and quality. Medicaid pays for 67 percent of all nursing home residents, and it has a tremendous effect on how nursing homes behave. How can systems be structured more effectively so that increased payments translate into better quality of life for residents and higher wages for workers, rather than more profits for nursing homes?

Aside from wages, benefits, and job conditions, other workforce issues cry for attention. Creating training programs in Spanish and other languages, for instance, would help the industry reach more potential workers. Assistance is also needed in developing recruitment systems that are not advertisement-based but more grass roots-oriented by reaching churches, parks, and community centers. In addition, cultural competency training programs would help to better connect patients with the workers who are caring for them. Bridging that cultural gap is very important for both.

Grantmakers can also create partnerships with policymakers, labor, providers, and consumer groups to drive the improvement of long-term care. These groups are not natural allies and could benefit from leadership from grantmakers to help them set aside their own agendas. One example of this kind of work is creating a central place where best practices and other information can be exchanged. A national clearinghouse would give people better access to innovative programs that are making a difference in long-term care.

Finally, much remains to be done in the area of family support and consumer advocacy. Nursing home residents, many of whom are cognitively impaired, need assistance in standing up for their rights as patients. Families who support these patients in nursing homes or in their own homes also need help. Dissemination of materials, safety assessment programs, and support groups can help residents, and help assure our nation's frail elderly can live the best life possible in their later years.

## FLINN FOUNDATION: LESSONS LEARNED

"The Arizona Alzheimer's model is not the New Mexico Casa program," said William Read of the Flinn Foundation. "While staff training and retention and patient care standards are high, other staff support activities were not adopted. We worry about this because of the increasing problems in recruiting and retaining caregivers and its impact on patient care."

During the Issue Dialogue, Read shared several other lessons learned in developing and implementing this project. Among them:

- Involve the executive leadership of participating provider organizations. While the foundation did this at first, it was curtailed during the middle years, resulting in potential and real cutbacks in program support from chief executive officers who were not familiar with or had lost track of the project's aims. The foundation re-engaged these CEOs during the course of program development.
- Don't discriminate against certain types of providers. Concerns about funding for-profits were overcome by making grants to the 501(c)3 education foundation of the Phoenix Alzheimer's Chapter, ensuring no grant dollars would directly go to participating organizations. If this new long-term care program was to be successfully introduced, for-profit providers had to be included as they represented the majority of long-term care providers in Arizona.
- Expect to keep a project such as this on the front burner. "Every time something went a little off course with the program, it was because I was paying too much attention to something else," Read said. He instituted monthly meetings with the grantees and convened all program participants on a regular basis.
- A foundation must address many different points of influence in order to introduce and institutionalize a new program. In long-term care, influence comes from the regulators, payers, consumers, policy leaders, advocacy organizations, private industry, and ultimately, state legislators. "They must all be involved from the get-go."
- Foundations must take a long-term commitment to this type of project. A few years of funding might get a similar program started, but will not sustain it over the long haul. It takes several years to make a real change in the organization and delivery of long-term care services.

Currently, the Arizona Medicaid agency is evaluating whether or not to include the model in its mandated array of services. The model programs are providing care at significantly lower costs, and this does not count the savings from reduced hospitalizations, emergency room admissions, and medications.

In conclusion, Read stated "… once patients are placed in these new settings, their families and staff do not want them to leave. [The patients] are aging in place, and I think the state Medicaid agency is beginning to see that this is all right."

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