



Out of the Shadows

ENVISIONING A BRIGHTER FUTURE FOR LONG-TERM CARE IN AMERICA



BROWN

A Brown University Report for the National Commission for Quality Long-Term Care

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The National Commission for Quality Long-Term Care was established in late 2004 to evaluate the quality of long-term care in the United States, to identify factors influencing the ability to improve quality of care, and to recommend national goals for quality improvement in long-term care. The Commission is co-chaired by former Senator Bob Kerrey and former Speaker of the House Newt Gingrich. Funding for the Commission has been provided by Alliance for Quality Nursing Home Care, the American Association of Homes and Services for the Aging, and the American Health Care Association. The Commission was initially administered by the National Quality Forum—a private, not-for-profit quality improvement organization that appointed the original members of the Commission in consultation with leaders and advocates from the long-term care community. In the spring of 2006, The New School for Social Research in New York assumed administrative responsibility for the Commission. Additional information may be found at www.qualitylongtermcarecommission.org.

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The opinions expressed in this report are those of the authors and not necessarily those of the National Commission for Quality Long-Term Care or The New School.

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Preface

AFTER YEARS OF ACCUMULATED PROBLEMS, the long-term care system in the United States is threatening to collapse under the massive weight of the aging Baby Boom generation.

It is a system full of contradictions—on the one hand, blessed with many capable and generous caregivers and with individuals grateful to receive that care, and on the other, plagued by the powerful negative influences of isolation, frustration, and fear. Indeed, individuals who need care at home or at a skilled nursing facility often feel isolated from family, friends and the greater community. They are frustrated by their inability to perform the daily tasks they have performed without thought their entire lives, and they fear the loss of dignity and humanity as body and mind inexorably weaken. Their families, struggling to navigate a maze with few signposts, can feel equally torn as they attempt to arrange appropriate funding and services. And conscientious providers struggle with similar challenges. While most try to do the right thing for individuals in their care, they often feel isolated from an acute health-care system that subtly shuns them, intensifying frustrations stemming from deep-seated financing and workforce woes. Moreover, providers are fearful—like those they serve—that the broader society will turn further away from them as the problems of long-term care inevitably deepen.

The purpose of this report is to inform the work of the National Commission for Quality Long-Term Care as it heightens awareness and formulates policy solutions to the long-term care conundrum facing the nation.

Executive Summary

THIS REPORT IS BASED on the growing recognition that loneliness, helplessness, and boredom plague the provision of long-term care in the United States, and that these are symptoms of the isolation that permeates the entire system, from financing to workforce to the continuum of long-term care services. In addition to describing the current state of the problem, the report examines six issue areas facing policymakers: financing and insurance, supporting and educating caregivers, the challenges of changing the physical and organizational environments in which services are delivered, recruiting and retaining a qualified workforce, designing a more effective regulatory control system, and adapting and integrating health information technology to long-term care. The report is the product of an in-depth examination of the literature, statistical analyses of data, and testimony provided to the Commission by outside parties. It is also informed by interviews conducted with 39 individuals, including 14 commissioners and 25 experts representing academics (12), current or former government officials (11), industry representatives (6), aging advocates (5), intergovernmental lobbyists (2), and others (3).

Statement of the Problem

Today's frail elderly and their family caregivers are frustrated by the disjointed array of federal and state policies that reimburse, regulate, and stimulate the development of long-term care services. They are dissatisfied with the limited choices in the kinds of services available to them, particularly if they are not wealthy. Most important, older Americans and their families fear the thought of entering a nursing home with the loss of control and individuality associated with these institutions. They would prefer increased investments in community-based services that make it possible for them, taken together with the help of their families, to remain as independent as possible in their own homes.

With ongoing improvements in life expectancy over the course of the next decades, we can expect that further increases in Alzheimer's disease and in functional disability will go hand-in-hand with the aging of America. Under optimal conditions, we have some time before the real "tidal wave" of the aged population is felt in the U.S.; but if we the people, both as the government and as private citizens, do not begin now to plan for this increased demand for services, it is not clear how we will manage. The U.S. is currently "younger" than many other industrialized countries, all of which are grappling with similar issues—but in 30 years, the leading edge of the "baby boom" generation will reach 85, the height of long-term care use. This means there is a limited amount of time to plan and then implement financing and delivery systems that meet the needs of the coming elder revolution.

The process of change must therefore begin now, both for the sake of future generations and for the sake of those struggling in the current environment. Six areas of concern must be addressed if we are to create a fair, comprehensive, affordable, and efficient long-term care system: financing, resources, infrastructure, workforce, regulation, and the introduction of health information technology. Each area is

complex but essential to address if we are to meet the challenges facing us today and in the future. Ultimately, the goal is to create a long-term care system that:

- Prioritizes use of public and private funding sources to further the establishment of equitable, comprehensive, and accessible long-term care financing covering all Americans;
- Empowers individuals and families by connecting them to the services, information, and resources that could ease their burdens;
- Promotes physical and organizational changes that enhance the lives of long-term care recipients and the careers of the people who care for them;
- Invests in the recruitment and training of adequate numbers of direct care workers and other staff capable of delivering high-quality care to long-term care recipients;
- Modernizes regulatory controls and incentives by regulating “smarter” and more consistently, improving and then maximizing the use of data already collected, and integrating the precepts of quality improvement and regulatory oversight; and
- Leverages health information technology through adoption of interoperable IT systems stimulated by increased investment, partnerships, and inclusion of long-term care providers and vendors in government-sponsored standard-setting entities and initial electronic health record designs.

Prioritizing Long-Term Care Financing

Current financing for long-term care is a complex mixture of private and public funds. As might be expected given the lack of clarity about what constitutes long-term care and how it is paid for, a majority of Americans are surprised to learn that Medicare does not cover use of extended long-term care services, whether at home or in a nursing home. This confusion applies to self-funding for long-term care; one-third of adult Americans believe they have private insurance coverage for long-term care in spite of the fact that less than 10 percent of the elderly have such a policy. Clearly, confusion generated by current public and private financing models is considerable and must be addressed if the nation is to cope with the coming wave of increased demand represented by the Baby Boom generation.

There is general agreement that, to date, high prices, public mistrust, and a lack of uniform standards have stymied growth in the private long-term care insurance market. Thus, private insurance is held by a small number of individuals and was estimated to pay for only about four percent of all long-term care costs in 2004. Furthermore, although nearly two-thirds of all nursing home beds are occupied by Medicaid recipients and just under 50 percent of all nursing home expenditures are reimbursed by that program, public financing of long-term care has been hampered by conflicts between Medicaid and Medicare policies that affect residential and home- and community-based services. Given the future needs of the population, the nation must grapple with how to pay for long-term care in both the near and long term. This will require instituting equitable, comprehensive, and accessible long-term care financing for all Americans.

Empowering Individuals and Families

Nearly 80 percent of adults who receive long-term care at home are served exclusively by unpaid caregivers. While caregiving poses a minimal burden for some and can, in many cases, be a highly rewarding experience, it can also exact a considerable personal toll—physically, mentally, emotionally, and financially, and in terms of retirement insecurity, lost jobs, or other missed opportunities. Most chronically ill and disabled individuals would prefer to live independently in their homes and communities. Although institutions continue to dominate in most states, state and federal investment in home- and community-based services (HCBS) has increased substantially over the past decade. Several states also provide for reimbursement of informal caregiver services in connection with Medicaid and other programs. Respite care, which provides unpaid caregivers occasional relief, is particularly important in this regard.

Very few people are prepared for long-term care when the need arises. Further, more than half the population would not know where to turn for advice or information if they or a family member needed nursing home care. Thus, there are two information problems: a prevailing lack of understanding about the importance of financing and personal preparation for the risk of long-term care, and a dearth of information about how to access needed services regardless of the ability to pay. We must address this information crisis if we are to empower individuals and families to plan for frailty, connecting them to services, information, and resources to meet their needs. In addition to a marked need to support family caregiving with greater formal and in-home support, there is a need for educational campaigns aimed at improving consumer knowledge, expectations of quality, and private planning for long-term care. Care coordination and counseling services that help individuals and families choose safe and effective options also need to be improved.

Promoting Physical and Organizational Change

In response to generalized complaints about the quality of long-term care services, pioneering organizations throughout the United States are beginning to transform the culture of long-term care. Among nursing homes, this transformation is reflected in the notion of overcoming institutionalism through congregated small group homes where residents drive their own lives and are supported by self-led work teams. Similar concepts have also been embraced in the context of continuous quality improvement, innovative end-of-life care, and home- and community-based settings. The common thread is a desire to revolutionize how chronically frail and disabled individuals live and are treated.

Ideally, life, both inside and outside an institution, should consist of activities that, according to the World Health Organization and Milbank Memorial Fund, “ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment, and human dignity.” Adoption of the person-centered approach—which places care recipients and/or their families at the center of the caregiving process—requires that long-term care providers respond to the values, preferences, and care needs of recipients while incorporating them into the fabric of their local communities. Patient participation, client autonomy, and shared decision-making are emphasized. So, too, are the benefits to providers who embrace these concepts and the innovation and culture-change efforts necessary to procure them.

Investing in the Long-Term Care Workforce

A well-trained, stable workforce—with professionals and paraprofessionals such as certified nurse assistants, home health aides, personal assistants, licensed practical nurses, registered nurses, nurse supervisors, physicians, social workers, pharmacists, administrators, and therapists specializing in care for the chronically ill and disabled—is a necessary prerequisite for quality long-term care. This goal has proved increasingly difficult to achieve, however, as market forces, poor management, and the poor reputation of long-term care providers make recruitment and retention of quality staff increasingly difficult. Annual turnover rates for most staff categories in both home and nursing home-based care are about 50 percent—sometimes even higher depending on the tightness of the labor market. Recruiting and retaining staff is especially problematic given the relationship between staffing and quality of care demonstrated in nursing homes and other settings.

There are several reasons that staff find long-term care unattractive, or choose not to stay after entering the field. Part of the explanation has to do with the “second rate” status associated with working in this area; this, despite the physically and emotionally demanding nature of the work. The long-term care workforce is also among the lowest paid in the nation with paraprofessional direct care workers earning a median hourly wage of \$9.20 in 2003, nearly 33 percent less than all U.S. workers. Direct care staff are also less likely to be offered full-time work and benefits, including health insurance, vacation time, tuition assistance, pension coverage, and child care. Because of the significant costs of inadequate recruitment and retention, it is critical that the existing workforce be expanded, supported, and trained for the multiplicity of tasks and responsibilities they will need to undertake in a reorganized long-term care system. Potential options include expanding loan forgiveness and scholarship programs, funding online training and education, and increasing wage pass-through initiatives to improve the circumstances of most direct care workers.

Modernizing Regulatory Controls and Incentives

Current regulatory practices in the long-term care field are based on inspections of patients’ records, observations of patients and care practices, and a review of policies and procedures. There is a strict divide between the regulators’ role of inspecting and sanctioning providers and the very different role of advising, educating, or consulting with providers. The latter is designed to improve quality, the former to assure quality. Many feel that the provider’s appetite for quality improvement may be limited as long as the principal critic that must be satisfied is the inspector. Whereas the nation’s quality improvement organizations (QIOs) can be seen as the government’s effort to provide the consultative information and support for providers to help them improve and solve their quality problems, state inspections serve an independent evaluative function that merely determines whether providers’ activities meet existing standards. Ideally, government regulation would be an iterative process in which inspectors identify performance problems and QIOs then help providers design quality improvement interventions to ameliorate those problems.

Reforming the current regulatory structure also requires that we regulate “smarter” and more consistently, in part, by improving and then maximizing the use of the data already being collected. Indeed, one of the most disconcerting characteristics of current regulatory authority is its inconsistent application both within and across states over time. There is also inconsistency in federally-mandated clinical assessments, which, together with the lack of consistency in inspection, casts doubt on the usefulness of publicly available data meant to aide consumer decision-making. Together these inconsistencies call out for improvements in the quality of the data used and the processes by which it is assembled. One strategy for improving the quality of the clinical assessment data is to introduce “real time” internal consistency checks for any given assessment as well as between assessments of the same individual. Improved data could then be used to generate reports on operational and quality performance for both internal and external uses.

Leveraging Health Information Technology

In no area are the potential “returns on investment” from innovation as significant as in health information technology (HIT). Unfortunately, HIT has been slow to spread, often with tragic consequences for patients and the continuity of their care. Indeed, even more than the acute care sector, long-term care, whether at home or in residential settings, is deficient in the application of HIT. Perhaps the most significant barrier has been the piecemeal development of the necessary telecommunications infrastructure, which promotes adoption of technologies that cannot speak with one another. Inclusion of long-term care industry representatives into the governance of state- and federally-funded standard setting entities would go a long way toward promoting interoperability and increasing the likelihood that long-term care patient needs are incorporated in initial electronic health record designs. Given high initial and ongoing maintenance costs, additional federal and state assistance—in the form of grants, reimbursement, and continuing support—would also likely increase the ability of some long-term care providers to sustain HIT over the long run.

Data deriving from more widespread adoption of HIT in long-term care would have utility for a multiplicity of audiences and uses. Not only would it increase the ability of government to regulate “smarter,” but it would better enable providers to track patients’ care across the all-too-frequent transitions frail elders make between long-term care service locations. Although most long-term care organizations have yet to develop data-sharing arrangements with hospitals, hospitals are increasingly building information technology systems to integrate inpatient and outpatient records, including those in physicians’ offices. Given the high proportion of Medicare hospital discharges referred to post-acute care, incorporating nursing homes and home health agencies into these networks is clearly desirable. This will only come about if long-term care organizations partner with hospitals to develop electronic communication systems that, in an effort to reduce errors, improve quality, and better monitor patients, enable the seamless transfer of patient-level data from one care setting to another. Further integration of cutting-edge telemonitoring technologies into long-term care settings should also be encouraged.

Chapter I

Statement of the Problem

TODAY'S FRAIL ELDERLY and their family caregivers are frustrated by the disjointed array of federal and state policies that reimburse, regulate, and stimulate the development of long-term care services. They are dissatisfied with the limited choices in the kinds of services available to them, particularly if they are not wealthy. Most important, older Americans and their families associate the thought of entering a nursing home with loss of control and individuality. They would prefer increased investments in community-based services that would make it possible for the frail elderly, with the help of their families, to remain as independent as possible in their own homes.

To allow for more, higher-quality long-term care service choices, individuals, families, and the state and federal governments must devise a viable system to finance long-term care and a coordinated delivery system that is responsive to consumer preferences. Although Medicaid financing for long-term care may appear to be at a crisis point, it will actually be 25 years before the leading edge of the "baby boomers" reach age 85, the height of long-term care use. This means there is a limited amount of time to plan and then implement financing and delivery systems that meet the needs of the coming elder revolution. The scope of the coming need and the deficit of preparedness mean that we can not afford to wait any longer to begin the serious work ahead.

"Without a soul—that's how I would describe the current state of long-term care. By this, I mean that we are without an abiding social purpose that we as a society buy into collectively. We have an industry that works in long-term care and people who work in long-term care, but we lack a common articulated set of values that guide the provision of long-term care in the United States."

— Judy Salerno, M.D., Commissioner

Demographic Trends

Today, an estimated 10 million Americans require assistance with basic personal activities of daily living from another person either by virtue of physical infirmity or cognitive impairment (Rogers and Komisar 2003). While over one-third of these individuals are under 65 years of age, most are older Americans living in the community. Indeed, since only a minority of those with long-term care needs reside in nursing homes, the largest share of the burden of meeting Americans' long-term care needs falls on families and other community-based caregivers (Figure 1).

Who Needs Long-Term Care? 10 Million Americans

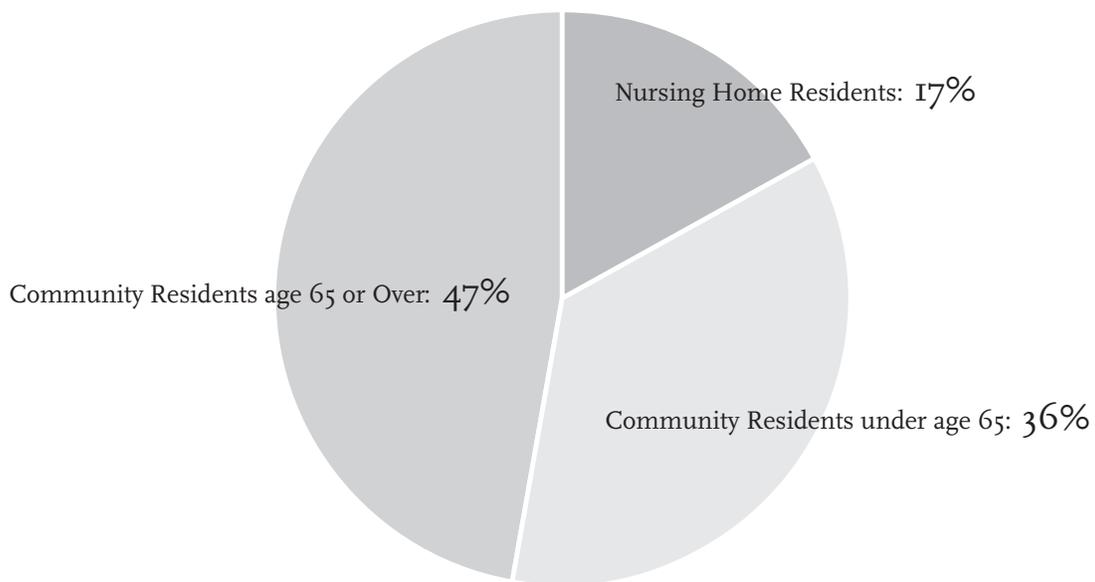


FIGURE 1

Source: Rogers and Komisar 2003.

Being dependent upon others for assistance with daily living tasks increases with age; about 16 percent of those aged 85 or older have difficulty getting out of bed, compared to 7 percent of those past the age of 70 (Federal Interagency Forum on Aging-Related Statistics 2006). Since long-term care needs are so strongly related to age, the impending growth of the older population in the U.S. means that the number of functionally and cognitively impaired individuals will increase

substantially. Today just under 13 percent of the U.S. population is over 65; by 2050, more one-fifth of the population will be that old (Figure 2). Similarly, as seen in Figure 2, whereas now 1.5 percent of Americans are aged 85 or older—the population group at greatest risk of needing long-term care support—by 2050, that figure will reach 3.8 percent; the number of Americans aged 85 or older will more than triple during this span, from 4.1 million to 15.8 million (Federal Interagency Forum on Aging-Related Statistics 2006). Furthermore, life expectancy continues to rise beyond projections, a phenomenon that will further increase the demand for long-term care.

Increasing Aged in U.S. Population

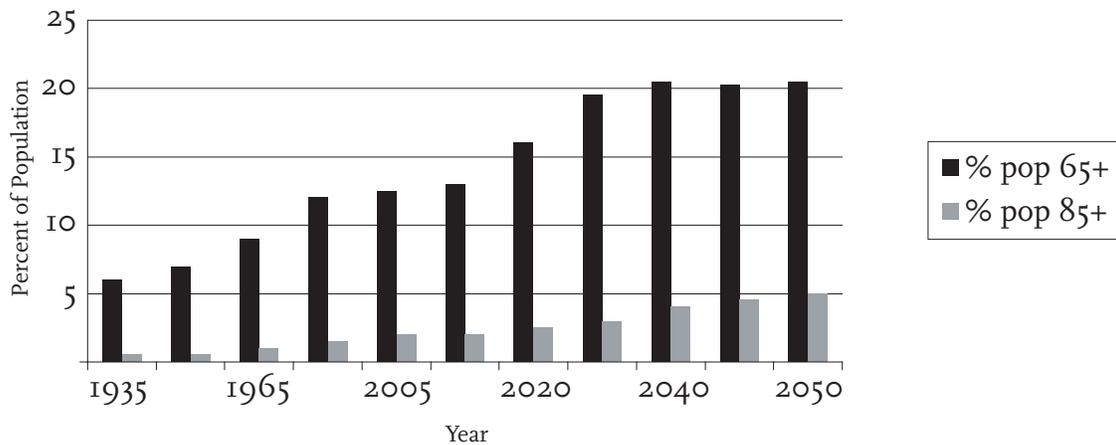


FIGURE 2

Source: Federal Interagency Forum on Aging-Related Statistics 2006.

Figure 2 reveals, however, that there is time before the dramatic growth of the “oldest-old” begins. The proportion of the population that is aged 85 or older is projected to remain relatively stable in the U.S. over the next several decades, with rapid growth beginning only when the first wave of the “baby boom” generation hits 85, after 2035. Indeed, according to the U.S. Census Bureau, the United States is much “younger” than virtually all other industrialized countries; indeed, the age demographics of European countries and Japan have already begun to look like the U.S.’s projected demographics 30 years from now (Friedland and Summer 2005).

Any increase in the size of the population requiring long-term care, regardless of age, implies increased demand for support from formal, institutional, and home- and community-based caregivers, as well as familial and other informal providers. The increasing prevalence of Alzheimer's disease (AD) also contributes to the demand for long-term care services and assistance provided by family members. About 4.5 percent of Americans are estimated to have AD, and most of these individuals are unable to manage their daily care tasks independently (National Institute on Aging 2006).

Since the prevalence of AD doubles every five years after age 65, by 2030 the number of persons with AD is projected to grow to 7.7 million; by 2050, when the bulk of the baby boom reaches age 85, there will be over 13 million persons with AD (National Institute on Aging 2006).

The increase in the aged population is occurring due to two factors. First, at 75 million births, the birth rate of the "baby boom" generation greatly exceeded that of prior generations. Second, since the dawn of the 20th century, older Americans have experienced unprecedented increases in life expectancy. Whereas a person who reached age 65 when the Social Security program began could expect to live another 12 years, today a 65-year-old can expect to live another 18 years (Federal Interagency Forum on Aging-Related Statistics 2006). When "baby boomers" begin reaching 65 they will be expected to live 20 more years—without accounting for any additional medical breakthroughs.

Data about the proportion of older Americans who have long-term care needs have consistently revealed declines in disability and dependency over the last several decades. Indeed, information synthesized from multiple sources reveals progressive reductions in the rates of dependency and institutionalization over the last thirty years (Figure 3). These same results suggest that, over the last half century, the average 65-year-old American has not only lived longer but has also spent a smaller proportion of those extra years in a disabled state. Indeed, between 1982 and 1999, the average 65-year-old American's proportion of remaining life years spent in an independent condition increased from 73 to 79 percent. Among those aged 85 or older, the increases in both life expectancy and disability-free life expectancy have been even more dramatic (Manton and Land 2000).

"Everyone will tell you that the reason to begin the reform process now is demographics. There are enormous financial, clinical, and ethical problems in long-term care. But to my mind, the heart of what we've done is paid long-term care very little money and then looked away except when there were scandals. Yet if we want to provide the best quality care we have to be prepared to pay for it. We have to be prepared to confront society—what resources are we willing to allocate? Indeed, this is a conversation that is already starting to take place—now that the baby boomers see what is happening to their parents, they can see themselves in that situation, too."

—Mike Millenson, Commissioner

Long-Term Trends in Disability among the Elderly

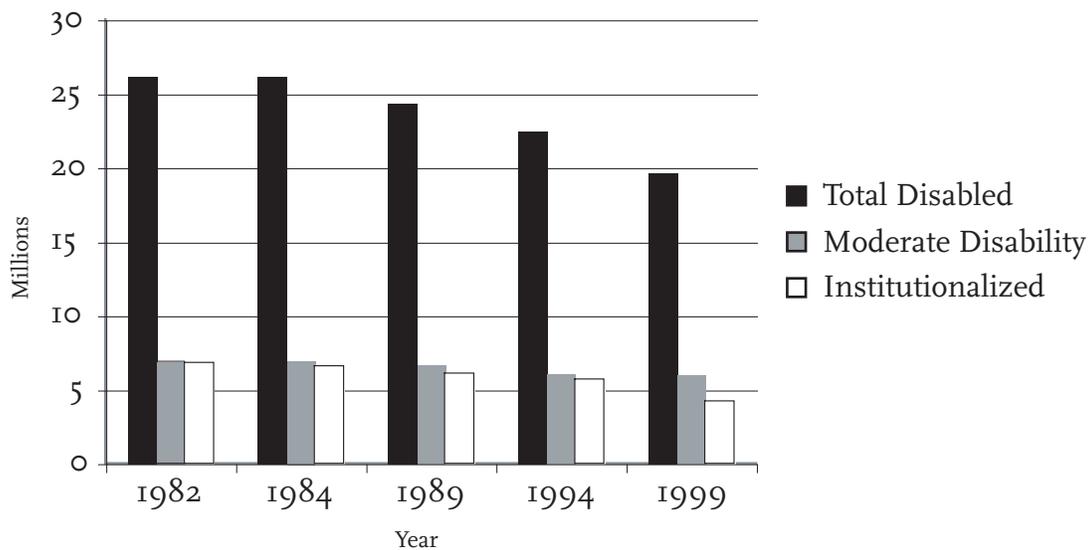


FIGURE 3

Source: Freedman, Martin, and Schoeni 2002.

Despite the fact that the rate of disability may be declining somewhat, and even if this trend continues over the next three to four decades, the absolute number of older disabled persons will increase substantially, simply by virtue of the large growth in the population and the increasing age of the elderly. As important, the increasing prevalence of obesity at all ages is bound to have a profound effect on the likelihood that older people will have functional dependencies requiring long-term care support (Reynolds, Saito and Crimmins 2005).

With ongoing improvements in life expectancy over the course of the next decades, we can expect that further increases in Alzheimer's disease and in functional disability will go hand-in-hand with the aging of America. Under optimal conditions, we have some time before the real "tidal wave" of the aged population is felt in the U.S.; but if we the people, both as the government and as private citizens, do not begin now to plan for this increased demand for services, it is not clear how we will manage.

The Long-Term Care Population

The estimated 10 million Americans with long-term care needs today are not all alike. Indeed, there are many different “paths” to dependency and the services such dependency requires. Some, often stimulated by dementia, experience a slow progressive decline and are increasingly unable to manage their daily lives. More often, this gradual progression is punctuated by illness, or accidents resulting in fractures and requiring hospitalization. Depending on how frail somebody already is, this event can precipitate a significant decline in functioning and an increase in the level of support required.

The complex interrelationship between functional dependency, cognitive impairment, and complex medical conditions was recently examined in a nationally representative sample of older Americans living in the community (Cigolle, et al., 2005). This study found that just under five percent of older Americans have three or more complex medical conditions, about 15 percent require assistance managing daily personal or household activities, and about six percent have significant cognitive impairment. At any given time, fewer than one percent (about 330,000 individuals) of elderly living in the community met all three conditions at once—but almost six percent met at least two of the conditions, suggesting that almost two million elderly individuals in the community are likely in need of long-term care support nearly on par with that required by the 1.6 million nursing home residents in the United States.

At any given time, the elderly long-term care population is composed of two different groups: the very old functionally and cognitively impaired individuals whose medical conditions are relatively stable but who require significant ongoing assistance with daily personal care, and those either recovering from a catastrophic medical event requiring extended recuperation or those who are dying from such. The first group includes individuals generally understood to be recipients of long-term care services and support, occupying nursing home beds and remaining in those beds for relatively long periods. Early on in their decline these individuals may reside in assisted living facilities, attend day care center programs, and receive home health agency support. They also rely on family,

friends, and other informal caregivers as they continue to deteriorate.

The second group of long-term care users are either short-term users of long-term care services because they recover or die, or because they are still relatively early in the trajectory of the medical conditions that underlie their eventual decline. It is difficult to separate those older Americans with long-term needs for support with personal care tasks from those whose impairment is more clearly attributable to a recent medical condition. At any moment in time, these populations may look quite similar, but the former are unlikely to recover their functioning and independence, while some of the latter group might, if only for a time.

An examination of Medicare beneficiaries in 2002 revealed that 93 percent of those aged 65 or older were living in traditional community settings, two percent in assisted living (group residential care settings providing at least some personal care and supervision), and 5 percent in nursing homes. Among those aged 85 or older, almost three quarter were still in community settings, 7 percent lived in assisted living, and the remainder in nursing homes (Federal Interagency Forum on Aging-Related Statistics 2006). Compared to 65 percent of nursing home residents, nearly 10 percent of elderly individuals living in the community were functionally impaired and required assistance in at least three personal care tasks (Figure 4). Although only 12 percent of assisted living residents needed help in three or more personal care tasks—thereby resembling those living at home and not in nursing homes, 33 percent had limitations in one or two personal care task areas, well exceeding the 19 percent requiring assistance with one or two tasks living at home. Clearly, there are differences among Medicare beneficiaries residing in different kinds of settings, with the rate of impairment increasing progressively from traditional community to assisting living to nursing home settings.

Percentage of Medicare Enrollees Age 65 and Over With Functional Limitations, by Residential Settings, 2002

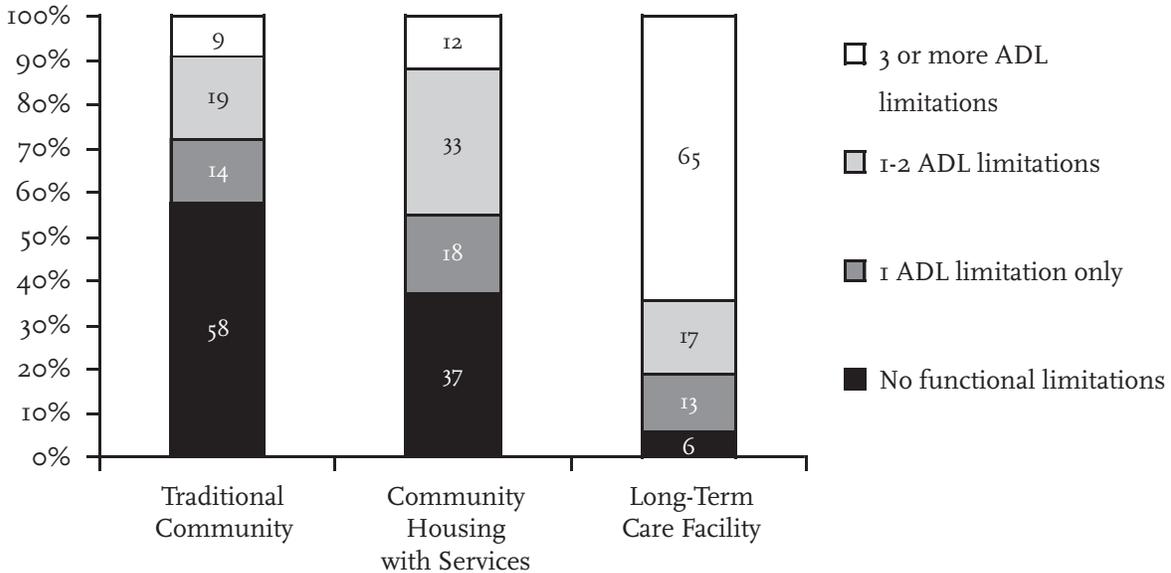


FIGURE 4

Source: Federal Interagency Forum on Aging-Related Statistics 2006.

The rate of hospitalization among those aged 85 or older in 2002 was more than 600 per thousand, suggesting that a high proportion of those aged 85 or older are hospitalized due to age-associated diseases and the accompanying risk of further functional impairment (National Center for Health Statistics 2006a). Over the last decade, the average length of hospital stays among Medicare beneficiaries has declined from 8.4 to 5.9 days, putting increased pressure on those caring for frail elderly patients following hospital discharge. Indeed, in 2002, one-third of all Medicare beneficiaries discharged from hospitals used some form of post-acute care setting, predominantly a skilled nursing facility or Medicare-reimbursed home care (Medicare Payment Advisory Commission 2005b).

Many individuals enter U.S. nursing homes every year, with 2.2 million admitted from hospitals alone under Medicare's skilled nursing facility (SNF) benefit in 2002 (Medicare Payment Advisory Commission 2005b). Of nearly two million discharges per year from nursing homes, long-stay residents constitute just under half (Kasper 2005). The most common reasons for

nursing home discharge among individuals aged 65 or older were death (35 percent) and discharge to a hospital (29 percent). Discharges to the community (stable or recovered) represented 23 percent of all nursing home discharges. Among long-stay nursing home residents, about one-third reside in a nursing home for less than a year, one-third between one and two years, and one-third for more than three years (Kasper 2005). Since only a minority of nursing home residents are admitted directly from the community, the long-stay population consists predominantly of those individuals who failed to return home following a post-acute care episode.

Despite the increase in the size and average age of the population aged 65 or older in the last several decades, the size of the resident nursing home population has actually shrunk, suggesting that home care use and the use of alternative residential settings like assisted living have made up the difference (Bishop 1999; Federal Interagency Forum on Aging-Related Statistics 2006). Furthermore, studies of caregiving provided to chronically disabled elders at home clearly suggest that over 90 percent of these individuals receive informal care and that this rate has remained constant over the last two decades, regardless of fluctuations in the availability of formal home care and increases in the use of alternative residential care settings (Spillman and Black 2005). Indeed, fewer than 10 percent of disabled elders living in the community rely exclusively on formal home care services, in spite of the fact that the proportion of older widows living alone rose to nearly 70 percent by 2000 (Friedland and Summer 2005). The extensive literature on the amount of caregiving provided by family members and the toll it takes on the well-being, financial status, and health of the caregivers is well-documented (see Chapter III). Despite these consequences, no evidence accumulated in more than three decades of research suggests that formal agency services replace those provided by informal caregivers.

Long-Term Care Services

Older Americans with long-term care needs utilize a complex combination of residentially-based and community-delivered services from formal sources; for those living in the community, these services are almost always in addition to substantial amounts of informal assistance from family and friends (Spillman and Black 2005). Based on information from various studies, we estimate that on any given day there are some 430 older nursing home residents per 10,000 persons aged 65 or older, and an additional 280 living in some form of assisted living or congregate housing with services. Additionally, there are as many as 200 older persons per 10,000 living in the community using home care services of some sort, and perhaps as many as 100 per 10,000 who attend day care programs, daily meals at senior centers, and/or who have homemaker services. Altogether, about 10 percent of those aged 65 or older (~1,000 per 10,000) receive formal long-term care services. An estimated 20 percent of the elderly population has chronic disability needs (~7 million persons or 2,000 per 10,000), and it is primarily this group that uses services, suggesting that only about half of chronically disabled elderly individuals receive formal long-term care services. This calculation is reasonably consistent with Spillman (2004), who suggests that about half of community-dwelling chronically disabled persons receive support and that about one-quarter of all those with chronic disability reside in nursing homes or another residential care setting.

Nursing home services are the most identifiable setting for long-term care. However, the number of nursing homes has been dropping since 1985, even as the total number of nursing home beds has risen to 1.8 million and the average nursing home size has increased substantially. While the aggregate occupancy rate is about 88 percent, with substantial regional variation (National Center for Health Statistics 2006b), occupancy has been dropping. Furthermore, although the actual number of people using nursing homes has increased to the point that, in 1999, there were 1.3 nursing home discharges per bed, the number of nursing home residents per the population aged 65 or over has declined (Decker 2005). Indeed, over the last decade, the rate of admission under Medicare's skilled

nursing facility benefit more than doubled from 28 to 69 per 1,000 beneficiaries.

Over the last decade, nursing homes have become more suited to serving the post-acute population; just 2,000 of the nation's 17,000 nursing homes are certified to serve Medicaid residents only, as opposed to both Medicare and Medicaid residents. Furthermore, over the last decade, the acuity (degree of illness and impairment) of nursing home admissions and residents has increased significantly (Feng et al. 2006). Most analysts believe that these changes in the nursing home sector have come about due to two factors. First, the increased use of nursing homes as post-hospital discharge locations for rehabilitation and recuperative care; second, the growth in assisted living and other supportive residential settings, along with expanded home care, that provide some segments of the elderly population alternatives to nursing home care. The net result is that needier and medically more complex residents have begun to permeate into most nursing homes around the country (Zinn, Mor and Gozalo 2000).

Ascertaining the size, scope, and pattern of use of assisted living (supportive residential care) is difficult due to the absence of common definitions, uniform state licensure, and the rapidly changing nature of the package of services provided by these settings for their residents. Nonetheless, the prevalence of use of assisted living services across the U.S. for Medicare beneficiaries aged 65 or older is estimated to be 1.3 percent, with 36,000 assisted living facilities serving approximately 900,000 residents in 2002 (Spillman, Liu, and McGuilliard 2002).

As noted, residents of assisted living are considerably less impaired than residents of nursing homes. However, just as the acuity of the nursing home population has been increasing over the last decade, there has been an unequivocal upward shift in functional disability among assisted living residents. The percentage with no disability or with dependence only for household maintenance tasks declined from 25 percent in 1992 to about 15 percent in 1998, while the proportion with dependencies in three or more personal care tasks increased from 35 percent to more than half (Spillman, Liu, and McGuilliard 2002). The transitional nature of assisted living for many residents can be seen in the often referenced length of stay of less than one year. The average length of time residents

spend in assisted living during the course of the year is 258 days, compared with an average 183 days for nursing home residents. It is not entirely clear, but these trends suggest that today's elderly are not only delaying entry into nursing homes but delaying entry (when they can afford it) into assisted living facilities as well.

Home care services are difficult to characterize in a uniform manner, due to different funding streams and different types of home care agencies. The use of Medicare-reimbursable home health services grew dramatically in the early 1990s, only to plummet with the introduction of the Balanced Budget Act of 1997. According to the National Home and Hospice Survey, the rate of visits per 1,000 Medicare beneficiaries went from 3,822 in 1992 to 8,376 in 1996, but dropped to 2,295 in 2001 (National Center for Health Statistics 2004). The number of home care agencies also declined, from a peak of more than 11,000 to about 7,500 in the year 2000. Of the over seven million discharges from home care in 2000, virtually all were served by Medicare/Medicaid-certified agencies, with Medicare reimbursing for about two-thirds of all patient stays that year. Since home health is frequently used as a post-hospital service to facilitate community re-entry following a catastrophic medical event, it is not surprising that half of all stays reimbursed by Medicare lasted only 26 days. It is also not surprising that most (61 percent) received skilled nursing services only. By contrast, relatively few received homemaker (10 percent) or personal care (21 percent) services. Though nearly three-quarters (71 percent) of home health discharges end with the patient remaining at home, 13.7 percent are re-hospitalized (half within 17 days). At 2.6 percent, relatively few discharges enter nursing homes, suggesting the rarity of home health-to-nursing home transitions.

A variety of other long-term care services, ranging from adult day care to meals on wheels, transportation and respite care, are present in many urban and suburban communities around the country, but the supply, availability, and funding mechanisms vary dramatically as a function of state policies regarding investment in home- and community-based services for the elderly and disabled (see Chapter III). National estimates suggest that the 3,500 adult day centers in the country are less than half the number experts believe are necessary to meet the expressed preferences of older persons

and their families to remain at home (Robert Wood Johnson Foundation and Wake Forest University School of Medicine 2002). Further, demand for respite care—which provides unpaid caregivers occasional relief from their caregiving duties—is currently estimated to greatly outstrip supply, though state officials attempt to respond to caregivers’ demand for respite services before offering other home- and community-based options (Kosloski and Montgomery 1995; National Alliance for Caregiving and AARP 2004).

The importance of states’ investment in home- and community-based services was borne out by Komisar, Feder and Gilden’s (2005) study of dually eligible (Medicare and Medicaid) recipients, which found that 58 percent of people needing long-term care report unmet needs and experience serious consequences, such as falls. Although unmet needs are substantial in all six states studied, the authors found the greater the use and availability of paid home care in a state, the lower the likelihood of unmet needs, suggesting states’ policies can make a difference. However, there is dramatic interstate variation in the share of Medicaid long-term care expenditures devoted to care in the community as opposed to institutions, with some states spending close to 90 percent of long-term care funds on institutional care and others investing more than half in home- and community-based services (Burwell, Sredl, and Eiken 2005).

Balancing Investments and Improving Quality

As described in greater detail in subsequent chapters, concerns about quality loom large in all discussions of long-term care services. The public does not trust that their needs will be met in a nursing home, a view reinforced by periodic scandals about poor quality of care. Initially conceived as a more flexible, homelike environment, assisted living has come under greater scrutiny as a result of the increasing frailty and medical acuity of assisted living residents. Due, in part, to investigations revealing staffing shortages that led to significant quality problems in assisted living facilities (U.S. General Accounting Office 1999), more states are imposing uniform regulations on these providers, regulations that resemble those governing nursing homes (Spillman, Liu and McGuilliard 2002; Kissam, et al. 2003). Studies examining the quality of adult day, respite, and even home care have been far rarer than studies of institutional services, making it difficult to make general statements about the quality of services. Nonetheless, frail older adults and their informal caregivers greatly prefer services that make it possible for them to remain at home. So perhaps the most salient issue vis-à-vis home- and community-based services are their relative availability and dependability. That is, can families identify formal agencies that guarantee that the same good worker will deliver services in a timely fashion, day in and day out? Some studies of Medicare-certified home health agencies suggest that, as with nursing homes, state inspection efforts are not sufficiently rigorous to assure the provision of high-quality care (U.S. General Accountability Office 2002) (see Chapter VI).

In addition to concerns about quality, there is growing interest in balancing long-term care service investments. In response to consumer demand and preferences, almost all states are slowly but surely increasing funding for home- and community-based services. Whether via authorities “waiving” regulations governing how Medicaid funds are spent, or via state-only programs operated by state departments for the aging, even states that have historically favored institutional care have increased investment in non-institutional alternatives in recent years (Burwell, Sredl and Eiken 2005; Kitchener, Ng and Harrington 2005). At the same time, most states have experienced

increases in Medicaid nursing home payment rates, meaning that there will be limits to how much they will be able to invest in growing the capacity to deliver home- and community-based options (Grabowski et al. 2004). The challenge is that reductions in payments for nursing home care are likely to adversely impact quality, whereas without significant investments in home- and community-based care, the supply will be inadequate to meet the demand. Further, without the funding base of Medicaid and Medicare, it will be difficult for a robust private home care market to develop in all but the oldest and wealthiest communities in the country. Nonetheless, policy must clearly move in this direction to be consistent with the demand and preferences of the current, not to mention future, elders.

Despite widespread concern about quality and the prevailing preference for home- and community-based service, we have yet to reach a national consensus about the way in which long-term care should be delivered and financed in the United States. Unless we engage in a national debate regarding this issue, we will continue to find it difficult to develop a strategy to address current needs and those resulting from the demographic challenges ahead.

“It is my own belief, based on my professional and personal experiences, that the long-term system is horribly broken. It too often warehouses people. It is terribly inflexible. It too often lacks a homelike quality, even though for many it is their home. And there are lots of policies and regulations that have the unintended consequence of impeding quality care.”

—Richard Payne, M.D., Commissioner

IN 2000, SOME 10 MILLION Americans needed long-term supportive services at an annual cost of \$182.2 billion—nearly two-thirds of which was directed toward nursing facilities and other residential settings, which serve less than one-fifth of those in need each year (Freiman 2005). The bulk of these costs (~64 percent) were incurred by government, primarily through Medicaid and Medicare, which, though covering home care, spend the majority of their money on institutional services (Komisar and Thompson 2004). With the aging of the baby boom generation, the percentage of the GDP devoted to Medicaid and Medicare is expected to increase from 3.5 percent in 2000 to 8.2 percent in 2035 and 14.5 percent in 2075 (Walker 2002). Further, spending on long-term care for the elderly is expected to quadruple, with Medicaid expenditures alone reaching \$132 billion by 2050. Thus, although federal and state officials have increasingly expressed interest in addressing the rising costs of long-term care in the face of extant fiscal pressures, the current situation pales in comparison to what we face in the future absent any real change.

It is also important to remember that individuals and families face increasing pressure as well. Out-of-pocket expenditures for formal services constituted 21 percent of long-term care expenditures in 2002 (Komisar and Thompson 2004). Moreover, it has been estimated that informal caregivers, who provide care to more frail and sick people on any given day than all formal services combined, offset an additional 36 percent of total spending on long-term care for the elderly (Congressional Budget Office 2004). But despite the critical role that informal caregiving plays, declining fertility among the baby boomers and smaller family sizes means that the number of children on whom they will be able to call for daily assistance will be fewer (Congressional Budget Office 2004). Therefore, it is questionable whether we can count on family care to meet the future demand of a frail elderly population that will nearly triple in the coming decades. We must devise a more comprehensive national financing policy to pay for future long-term care costs.

Perhaps the most widely recognized burden of those dealing with the prospect of long-term care is the high cost of services. The average cost for a semi-private room in a nursing home was \$61,685 in 2004; home health aides cost \$18 per hour, on average, resulting in average annual costs of up to \$26,208 for four hours of daily care (Mature Market Institute 2004). These and other expenses associated with increasing frailty can have devastating financial consequences. Johnson, Mermin, and Uccello (2005) estimate that two-thirds of people aged 70 or over experience “negative shocks” over ten years, including diagnosis of a major medical condition, onset of severe physical or cognitive impairment, widowhood, and entry into a nursing home. These shocks were associated with both significant reductions in wealth and increased likelihood of falling into poverty over the time period analyzed. Because long-term care costs generally begin well into retirement, elderly people’s assets have typically dwindled long before as a result of rising medical costs.

Recently, researchers estimated that the average lifetime cost of home care necessary to avoid nursing home use was \$174,000 in 2002 dollars (Cohen, et al. 2005). However, the majority of elderly people living in the community today have very low levels of liquid assets; 57 percent have assets below \$5,000 and only one-third have assets sufficient to afford at least one year of nursing home care (Lyons, Schneider, and Desmond 2005) (Figure 5). Moreover, of those at greatest risk for nursing home entry—over 85, female, single, and disabled—only 15 percent had assets sufficient to pay for at least one year in a nursing home (Lyons, Schneider, and Desmond 2005).

Distribution of Elderly Living in the Community by Distribution of Assets, 2005

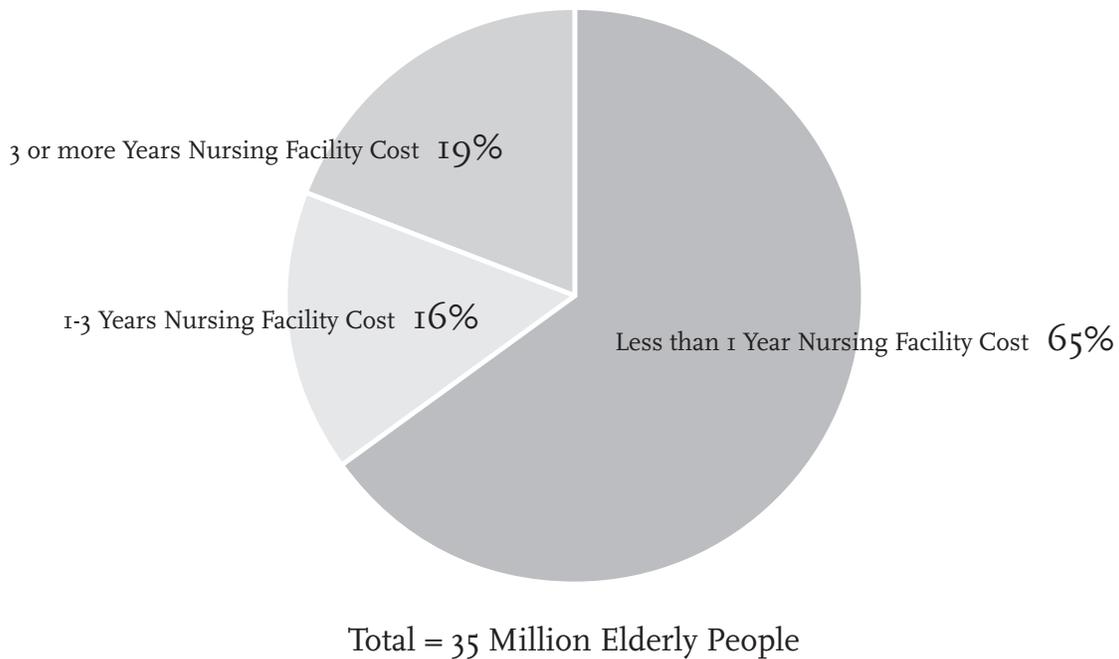


FIGURE 5

Source: Lyons, Schneider, and Desmond, 2005.

Since frail elders are increasingly beginning their long-term care careers in the community and in structured residential settings such as assisted living or continuing care retirement communities, expenditures on long-term care “services” will have begun long before permanent admission to a nursing home (if that event ever occurs). Merlis (2005) reports that only 32 percent of elderly households with individuals requir-

ing some long-term care services have financial assets sufficient to afford 12 months of home care costing about \$2,000 per month. When housing assets and the prospect of funding from “reverse mortgages” are considered, 92 percent would have funds sufficient to afford home care for one year (Merlis 2005). Currently, however, the high costs of home equity conversions and restrictions on the amount of funds made available limit the potential usefulness of this tool as a mechanism for paying for long-term care.

The baby boomers have neglected to plan for long-term care. A recent Employee Benefits Research Institute study concluded that fewer than 40 percent of baby boomers would have adequate retirement income even if they were to increase savings by five percent per year (Jaffe 2004). Indeed, most Americans do not think much about their prospects or needs later in life, and still fewer have saved adequately for retirement or made provisions for long-term care. A recent survey conducted on behalf of the Kaiser Family Foundation (2005) asked respondents from across the country about whether and how they had planned for long-term care (Figure 6). Responses reveal that few have given this matter much serious consideration. Just one-quarter had given “a lot of thought” to how they will pay for long-term care services, though the percentage increased from 23 percent for those aged 30 to 49 to 43 percent for those aged 65 or older. Limited resources and lack of preparation among the nation’s baby boomers suggest that the country is facing a huge financial obligation for which we are ill prepared.

“We’re headed toward a situation in which grandparents will be in direct competition with grandchildren over a finite dollar. And we are increasingly facing the prospect that the portion that goes toward senior issues, Medicare, and long-term care will come from the education accounts of our nation’s grandchildren. But that’s the last thing any grandparent wants. It will break their hearts if they think that somehow they’re taking money away from their grandchildren to have a better life.”

—Former Governor Dirk Kempthorne
of Idaho, Commissioner

Planning for Long-Term Care

When thinking about your financial needs in retirement, how much thought have you given to how to pay for long term care in a nursing home or home health care costs not covered by Medicare?

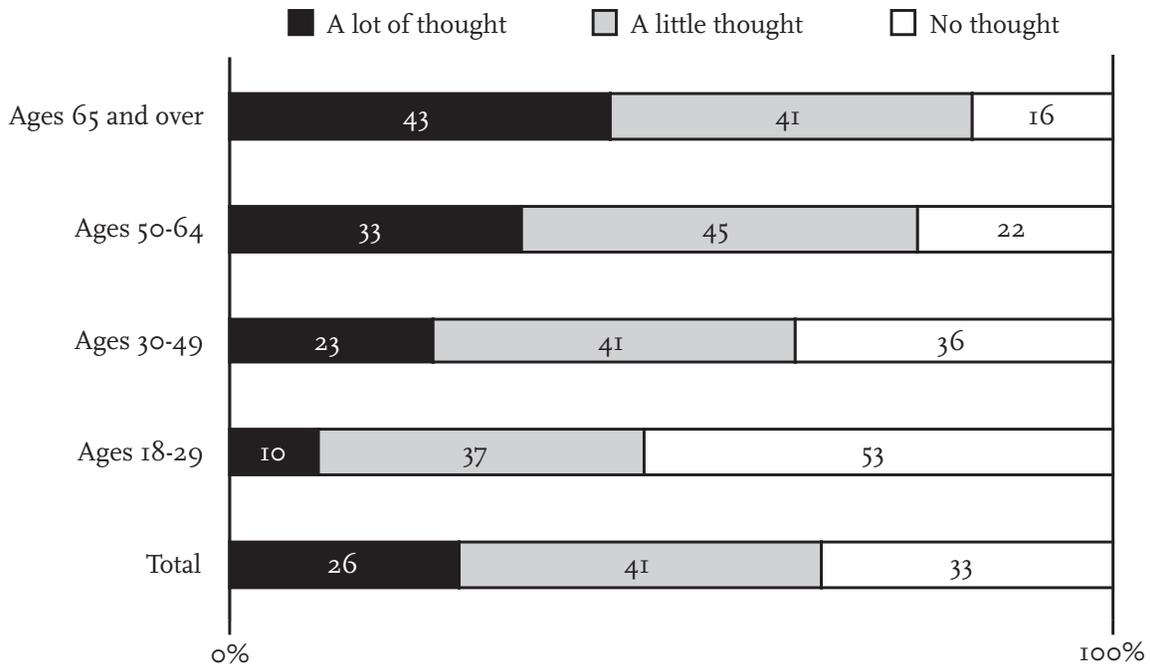


FIGURE 6

Source: Kaiser Family Foundation Health Poll Report Survey (conducted June 2-5, 2005)

Long-Term Care Insurance

Current financing is a complex mixture of private and public funds. As might be expected given the lack of clarity about what constitutes long-term care and how it is paid for, a majority of Americans are surprised to learn that Medicare does not cover long-term care, whether at home or in a nursing home (Kaiser Family Foundation 2005). This confusion extends to self-funding for long-term care; one-third of adult Americans think they have private insurance coverage for long-term care, when in fact less than 10 percent of the elderly have such a policy (Burke, Feder, and Van de Water 2005).

Only about 10 percent of long-term care funding derives from private insurance (Komisar and Thompson 2004). Although some 8.3 million private long-term care insurance policies had been purchased by 2001, only an estimated 5.8 million were still in force. In 2002, the latest year for which data are available, private long-term care insurance paid \$1.4 billion in claims, a small fraction of long-term care spending (Desonia 2004).

Several factors account for the low level of market penetration. First, premium costs put the product outside the financial reach of many people. Premiums range from \$300 per year for a 30-year-old to nearly \$2,000 per year for a 70-year-old. Further, most people are unfamiliar with the product and confused about coverage for long-term care under existing private- and government-based health insurance arrangements. Even with inflation protection, some estimates suggest that medical care inflation, which outstrips the general inflation on which such protection is based, could leave insured individuals with a progressively growing shortfall for future long-term care costs (Brown and Finkelstein 2004). Individuals must also continue to pay premiums on their policies for extended periods in order to keep them in force, but recent studies suggest that a large proportion of those who have purchased long-term care insurance allow their policy to lapse within five years (McNamara and Lee 2004).

Private long-term care insurance prices vary as a function of the scope of service, duration of benefits, and stringency of barriers to gaining benefits. Many policies have inflation adjustment options, but these tend to double premiums, particularly for younger beneficiaries. Policies also set a given maximum dollar

“You wouldn’t go without fire insurance. You wouldn’t go without car insurance. We need to tell people you can’t go without long-term care insurance. In my own instance, my long-term care insurance does not cover all of my husband’s care, but I can afford to pay the difference with that help. So I’m doing my share and my insurance is doing the other share.”

—Sandra Smoley, Commissioner

amount per diem, or per week, that will be paid by the insurer for a given service. In this sense, the benefit has a dollar cap, but there are also restrictions on the kinds of services that can be purchased. Policies also vary according to length of coverage; the more generous provide up to four years of benefits. A policy paying \$100 per day for four years would represent nearly \$150,000 in benefits. On the other hand, someone buying the average policy with inflation protection would pay some \$850 (in 2001 dollars) per year in premiums for 35 years (or nearly \$30,000) until, at age 85, they became likely to both meet policy criteria and use the policy. Indeed, while utilization and cost experience continue to accumulate in the private insurance market, pricing the policies is still a haphazard process involving as much concern about excessive loss ratios as about making sure premiums are high enough. This is largely due to the unknown risks associated with the kinds of “adverse selection” that occur when such a small proportion of the population at risk actually purchases the insurance product.

A recent analysis of pricing and benefit structure in the long-term care insurance market reveals substantial levels of “over-pricing” for men compared to

women relative to their known risk differences (Brown and Finkelstein 2004). The authors also found that the typical 65-year-old who buys a long-term care insurance policy is likely to receive only \$0.82 on the dollar in present value discounted benefits. Furthermore, the authors estimated that a typical policy covers only about one-third of an individual's long-term care costs; many insurers, however, offer policies that cover a substantially larger share of estimated long-term care expenditures.

Several projects have been instituted over the past decade to expand the demand for long-term care insurance. In the early 1990s, Congress established the Long-Term Care Partnership Program. Offered by four states—California, Connecticut, Indiana, and New York—this program allows individuals with modest incomes and savings to protect more of those assets (should they eventually require Medicaid-funded long-term care) if they purchase private long-term care insurance but ultimately require care for longer than their insurance policy covers. While attractive because the state serves as a kind of “re-insurer” for both the private insurance company and the consumer, this program has not grown as much as might have been expected, possibly because annual premiums exceed \$3,000 for two years of long-term care coverage (Foster, et al. 2003). Furthermore, due, in part, to concern about the quality of the policies being offered, Congress established a moratorium on new partnership programs beginning in 1993. The Deficit Reduction Act (DRA) of 2005 lifts this moratorium, however, allowing all states to establish partnership programs (Crowley 2006). Whether this model is sustainable in the long run for a large number of users is questionable, though, because states assume the risk for longer than expected insured-for periods and allow individuals to retain reasonably large levels of assets (Congressional Budget Office 2004).

Consumers might view the relatively recent phenomenon of private long-term care insurance as more akin to life or disability insurance in that many years of premiums are paid before any benefits are distributed. This means that consumers must trust that these firms will remain in place for the long haul (Lewis, Wilkin and Merlis 2003). Although great strides have been made in developing model standards for long-term care insurance policies over the past few

“If you are trying to increase confidence in private long-term care insurance, you’ve got to have Federal regulation, and that regulation has to acknowledge that this is a tough product to sell. It also has to acknowledge that not everybody can do this, and you don’t want everybody—‘You’ve got to have a considerable amount of expertise, and you need a hell of a lot of capital. So please don’t get into this business unless you’ve got the capacity.’”

—Former Senator Bob Kerrey, Co-Chair

years, only about half the states’ insurance commissioners have adopted such standards; among those that have, the means to monitor sales practices are quite limited.

The National Association of Insurance Commissioners (NAIC) recently updated its model policy regulations covering private long-term care insurance pricing practices; as of 2003, 14 states had adopted the new provisions limiting rate increases. Nonetheless, recognizing the real uncertainty in experience-based rate setting, the NAIC model gives insurers considerable leeway to raise premiums and provides no recourse for consumers who are no longer able to afford their policies after rate increases are imposed. Furthermore, not all states had adopted even the previous NAIC standards, and policies are not necessarily portable from state to state. Congress took a first step toward addressing these issues by including provisions in the DRA to require that all Long-Term Care Partnership programs adopt NAIC model standards and develop uniform

reciprocal recognition of partnership policies across states (Crowley 2006).

To give consumers greater confidence in the viability of the private long-term care insurance market, national standards are necessary. Private long-term care insurance market reform requires action at both the federal and state levels, as well as commitment from the long-term care insurance industry to abide by more uniformly applied and monitored regulations governing the policies that they issue. The literature suggests that the current array of long-term care products is both insufficiently flexible and insufficiently uniform to allow consumers to make informed choices. Thus, the insurance industry should adopt a uniform set of standards such as those recommended by the NAIC, expand the array of long-term care insurance products, and increase the flexibility of benefits within the current array of insurance products.

Public Funding of Long-Term Care

Nearly two-thirds of all nursing home beds are occupied by those receiving Medicaid, yet fewer than 50 percent of all nursing home expenditures are reimbursed by the program. This is because individuals become eligible for Medicaid only after spending down most of their assets or accruing medical expenses, including long-term care costs, which exceed their income. To prevent individuals with long-term care needs from transferring their assets to become Medicaid-eligible, federal rules require a “look-back” period; the look-back period allows states to recover assets that were divested while individuals spent down to meet Medicaid eligibility requirements. In light of anticipated rising demand for long-term care and states’ associated fiscal crises in meeting these entitlement costs, there have been numerous proposals to extend the look-back period, increase penalties for divesting, and more aggressively recover such assets.

The Deficit Reduction Act of 2005 tightened Medicaid eligibility rules related to asset transfers, including extending the look-back period from three to five years (Crowley 2006). Notwithstanding policymakers’ concern, however, relatively few individuals become Medicaid-eligible by transferring or divesting assets. Median transfer amounts are just \$2,800, \$3,000, and \$5,000, over a six-year period, for individuals who become eligible before, during, and after nursing home admission, respectively (Waidmann and Liu 2006).

In fact, most elderly individuals rely on private resources to pay for all or part of the costs of nursing home care. Nearly 40 percent of 65-year-olds will use a nursing home at least once in their lives; of these individuals, 44 percent will pay for their care using private funds alone. Only 27 percent will begin and end their nursing home care as Medicaid beneficiaries; 14 percent will spend down private assets before becoming Medicaid-eligible (Mor, Intrator, and Laliberte 1993; Spillman and Kemper 1995). Even among nursing home residents covered by Medicaid, most fund a substantial amount of their care through private resources, including their own retirement funds and Social Security.

Yet, despite significant private contributions, 17 percent of all persons who turn 65 can expect to receive Medicaid nursing home coverage at some point in their lives, with three-fifths of these becoming

Medicaid eligible upon admission rather than after having “spent down” (Spillman and Kemper 1995). Overall, Medicaid spending constituted 47 percent (\$84.7 billion) of national long-term care spending in 2002, with approximately two-thirds devoted to care provided in institutions and one-third to home- and community-based services.

Medicaid is the largest public payer of long-term care costs, but Medicare reimburses for “post-acute” care provided in nursing homes and by home health agencies; Medicare therefore ends up paying a substantial 17 percent of the nation’s long-term care bill (Komisar and Thompson 2004).

Because the state and federal governments have somewhat different agendas with regard to long-term care, Medicare and Medicaid often operate at cross-purposes, each striving to minimize spending for beneficiaries—regardless of the fact that acute and long-term management of functional and medical problems are often indistinguishable for the long-term care patient. Since states pay a share of Medicaid expenses, they are keen to maximize Medicare reimbursement for the long-term care services their Medicaid recipients consume; the federal government, by contrast, focuses on limiting its liability for “post-acute” care, seeking to establish and enforce restrictive eligibility criteria for services reimbursed by Medicare. Individuals with long-term care needs who do not qualify for Medicaid have interests similar to those of state government—maximizing Medicare reimbursement.

This pattern of incentives can work to keep non-Medicaid eligible, frail, older persons and their families from relying on formal long-term care services after their Medicare coverage has ended—but the consequence may be significant unmet needs (Komisar, Feder and Gilden 2005). For the dually eligible long-term care user—Medicare beneficiaries who also receive Medicaid services—the misaligned incentives of the state and federal government can lead to compromised care quality and continuity, as seen in rehospitalization rates and other clinical complications (Boult and Pacala 1999; Miller and Weissert 2003; Ryan and Super 2003). In fact, recent analyses conducted at Brown University suggest that patients discharged from hospitals to nursing homes in states with above-average levels of Medicaid nursing home reimbursement are significantly less likely to be re-

“I was making out a Medicaid eligibility form, all sixteen pages of it, for my mother. I counted up, and between my mother and father, we had spent \$400,000 on their care since they’ve become frail—and that is not high. That’s ordinary stuff over a period of time. That puts a little reality into the ‘affordability’ question. Long-term care isn’t affordable to anybody if they’ve been receiving help over an extended period. Somehow in all of this there has to be risk-sharing over a large pool.”

—Monsignor Charles Fahey, Commissioner

hospitalized within 30 days (Figure 7). Other analyses reveal that when states invest additional nursing home reimbursements in resources such as skilled staff, Medicare derives the benefit of reduced hospitalizations (Intrator et al. 2005). In states with low reimbursement levels, the opposite is true—nursing homes tend to have fewer skilled staff, translating into more than double the rate of hospitalization.

Perhaps motivated by the potential doubling of states’ Medicaid long-term care budgets in the next 20 to 30 years, a number of demonstration projects over the last decade have attempted to align the incentives for Medicare- and Medicaid-funded services by bringing them under a single funding or service delivery mechanism (Kronick and Dreyfus 2001; Miller and Weissert 2004). Most of these programs, which have been relatively small and focused on individuals who might otherwise be eligible for nursing home care,

Re-Hospitalization Rate within 30 Days of Nursing Home Admission by State in 2000

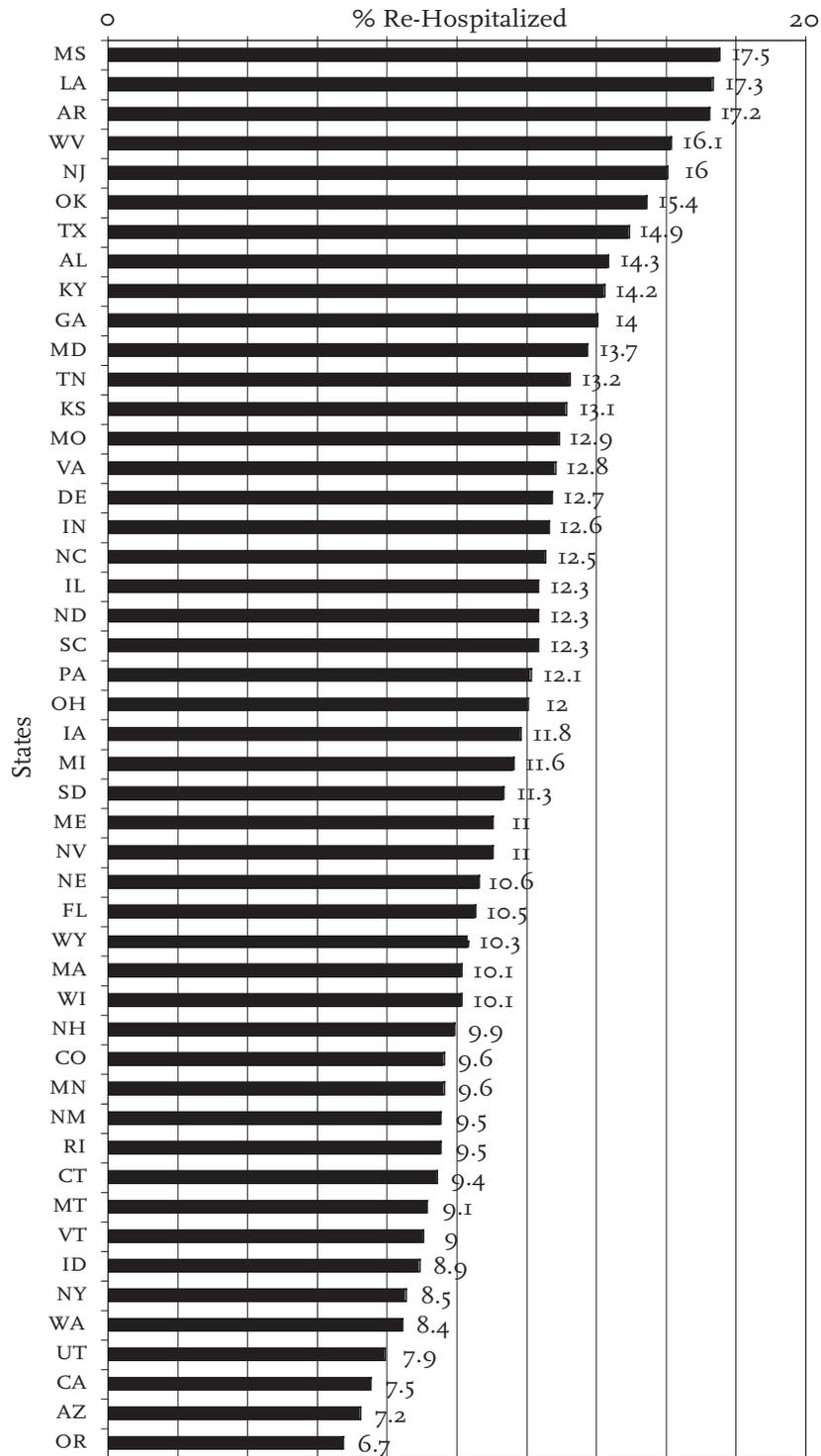


FIGURE 7

Source: Minimum Data Set (MDS) 2000; Medicare Inpatient Claims 2000

have served the dually eligible population. Evaluations of these programs over the last decade have tended to conclude that when acute and long-term care services are integrated, either through a financing or service delivery model, patients have lower rates of hospitalization. For example, the Program of All Inclusive Care for the Elderly (PACE), implemented in numerous states in programs ranging from several hundred to several thousand clients, results in shorter hospital days than the regular Medicare fee-for-service program (Chatterji 1998). Evercare, a Medicare managed care program focusing on nursing home residents, has also resulted in far fewer hospitalizations for nursing home residents than for similar, non-Evercare nursing home residents in the same state (Kane, et al. 2003).

To date, the only statewide effort to integrate Medicaid and Medicare funding for long-term care is the Arizona Long-Term Care system, which has restrained spending by ensuring enrollment of nursing home-eligible individuals only and by reducing hospital and nursing home use among program participants (McCall, et al. 1996; Weissert, et al. 1997). Perhaps most impressively, Arizona has organized integrated service delivery in the community for these frail patients, an exceedingly difficult accomplishment. One of the most-watched recent initiatives is occurring in Florida, which received permission from the federal government to provide capitated payments to regional managed care plans for all mandatory Medicaid benefits, including nursing facility and home care. The Florida plan will, for the first time, introduce nominal “co-pays” on beneficiaries (Kaiser Commission on Medicaid and the Uninsured December 2005).

Demonstrations such as these offer an opportunity to understand how the conflicted interests of the federal and state governments can be properly aligned to benefit the frail, dually eligible elderly. Of particular interest is ensuring the true integration of acute and long-term care services under Medicare and Medicaid and ensuring service adequacy in the face of incentives designed to reduce service use in a vulnerable population.

Not all individuals with long-term care needs are subject to the financial and administrative conflicts facing Medicare and Medicaid. The U.S. Department of Veteran Affairs (VA) operates the largest health care network in the country, both financing and providing medical care that is increasingly viewed as second-to-none in the U.S.

“I think we are going to struggle to get this thing right so long as the incentives facing the federal and state governments are so different. Every governor in the country today is putting together their next State of the State speech right now, and they are looking at their budget, and most of them have to be in balance. Medicaid is a growing share of their budget, and they are tormented by it. They don’t like having to cut actual expenditures or even slow the rate of growth, but they are forced into examining the consequence of the growth and into figuring out ways to compensate for it.”

—Former Senator Bob Kerrey, Co-Chair

The VA integrates patients’ acute and long-term care needs, and providers are held accountable for all care. We can learn from the VA’s experiences.

A significant legal and administrative barrier to effectively integrating acute and long-term care services is the prohibition of mandatory managed care participation among Medicare beneficiaries (Kronick and Dreyfus 2001; Miller and Weissert 2004). Medicare beneficiaries are reluctant to give up the opportunity to choose their medical care provider—one reason that most Medicare/Medicaid integration efforts have remained relatively small. Further, the administrative costs associated with populations that are chronically ill and have numerous co-morbidities are high for managed care organizations (or the medical practices assuming that responsibility), as well

as for the states that have to monitor quality to prevent abuses.

We may be able to draw lessons from the recent implementation of Medicare Part D, particularly for the dually eligible population that was automatically and randomly enrolled; for now, however, expanded demonstrations rather than comprehensive system change will need to be the vehicle for the integration of acute and long-term care services under Medicare and Medicaid. The Centers for Medicare and Medicaid Services (CMS) need to find vehicles that encourage dually eligible beneficiaries to enroll in health plans that combine Medicare and Medicaid and that emphasize the virtues of integrated care delivery, particularly for those with long-term care needs. CMS might stimulate states to move in this direction by developing innovative demonstration programs that credit states and providers, through Medicare funds, for estimated savings attributable to reducing unnecessary hospitalizations. Additionally, CMS should consider allowing states to develop programs that make it possible for “near poor” Medicare beneficiaries to “buy into” an integrated long-term care program in much the same way that states are allowed to enroll near poor women and children in Medicaid and the State Children’s Health Insurance Program (SCHIP). A similar approach could be followed in states that have operational “Cash and Counseling” programs—a waiver demonstration and new state option under the DRA that allows family and friends to be paid to provide personal care services to nursing home-eligible Medicaid recipients at home (see Chapter III below). An expanded version of this program might allow near poor families to buy into the “cash” payment options but still get the benefit of the advice and counseling.

“We manage transitions between acute care and long-term care very poorly to the detriment of patients. I would like to see a more close alignment of nursing homes with hospitals and home health providers within a system of care. I had the privilege of working in the VA, where we were able to do that much more closely and I saw how much better it could work. But we’re amputating long-term care more than we are integrating it, and that results in bad care—not because anyone intentionally provides poor quality care or because people are thoughtless or don’t care. It’s because the system doesn’t allow them to do things in a fashion that makes it easy to care for patients.”

—Judy Salerno, M.D., Commissioner

Stimulating a National Debate on Financing Long-Term Care

Deficiencies in current private and public long-term care financing models are considerable and must be addressed if the nation is to cope with the coming wave of increased demand posed by the Baby Boom generation. Low levels of retirement savings, low rates of private long-term care insurance purchases, and health and long-term care costs rising at twice the rate of inflation and GDP growth make it essential that we devise a set of solutions to avoid impending financial catastrophe. Nonetheless, as Commissioner Scanlon has noted, the need for long-term care is a risk, not a certainty (Scanlon 2004). Depending on how one defines long-term care needs, whether in terms of a stay at a nursing home or simply dependency at home, between 45 and 65 percent of those turning 65 years of age will require long-term care services (Spillman and Kemper 1995; Cohen, et al. 2005).

However, even among those entering nursing homes, only a small proportion will reside in such a facility beyond their Medicare-covered stay. Thus, long-term care need is an insurable event, much like disability during one's working years. It goes beyond retirement annuities, whether based upon defined benefits or defined contributions, since the claim on retirement is certain, whereas the claim on long-term assistance is not. Long-term care need is not income replacement due to disability; rather, it meets basic daily care needs that most people, even elderly and work-disabled individuals, can perform independently. How these needs are met, whether by paid, formal agency-based services or with assistance provided by family and friends, will vary as a function of individual, family, and local resources.

Calls over the past three decades for public sector involvement beyond Medicaid have foundered on incorrect assumptions about the demand for care and on muddled understandings of long-term care. Any healthy debate about the future of long-term care financing in the U.S. will have to address the following issues:

- Should at least some part of the solution be universal or voluntary?
- Should there be a private, public, or mixed model of financing?

“We need to come to a consensus about the medical services that people in the long-term care system need; the supportive services that they need; the role that Medicare, as a social insurance program, should play; the role that private insurance should play; and the role that Medicaid, as a welfare public assistance program, should play.”

—Former Senator David Durenberger,
Commissioner

- How closely to retirement benefits or disability insurance should a long-term care financing policy be tied?
- Should benefits be service entitlements or dollar-denominated allowances?
- How should contributions and benefits be phased in to cover those without an actuarially-based claim to the benefit pool?

Obviously, *universal* coverage for long-term care would avoid the problems of adverse selection, where those most likely to need long-term care choose to be covered and those unlikely to need long-term care choose not to be covered. It would also avoid the high costs of “marketing” the insurance/savings product, a necessity under a *voluntary* system. Indeed, some suggest that high long-term care insurance premiums are attributable to high sales commissions paid to those selling the policies (Lewis, Wilkin and Merlis 2003). Another obvious benefit of a universal system is that individuals can readily choose to supplement basic coverage at any point, independently or in conjunction with a combination of housing or other direct long-term care

services. Universal systems do not necessarily need to be administered via payroll deduction or income tax withholding, although those systems are already in place. An alternative funding model would involve premiums charged to the purchasing price of financial instruments like mortgages, credit card purchases, or pension fund earnings.

To date, *privately* funded long-term care insurance has not achieved a high degree of market penetration among either older or middle-aged individuals. Furthermore, it would be very unusual for a universal, virtually mandated program to be privately run. On the other hand, a *public* program, presumably operated through a tax or payroll deduction, might not necessarily engender more trust, particularly among younger generations, some of whom are already questioning the viability of Social Security for their own retirement. Since the federal government draws upon Social Security receipts for all operating expenses, some Americans might worry that adding long-term care insurance revenues would merely expand the pool of funds accessible for current federal deficit spending. An alternative approach, using a model like the Federal Deposit Insurance Corporation (FDIC) or an actuarially sound re-insurance pool managed by an independent trust, might overcome major objections to both private and public approaches, but the premiums would constitute significant capital resources that would need to be transparently managed outside the control of government, an approach for which there are relatively few successful models.

As noted above, long-term care needs differ from *income replacement*, which is characteristic of disability and retirement benefits. Most existing policies—including those of private programs and those of publicly funded programs under Medicaid (nursing home and home care)—have functional eligibility criteria based on the number of daily living tasks (bathing, dressing, getting out of bed, etc.) that one is not able to perform without assistance. Long-term care support—whether public or private—pays for assistance to perform those daily living tasks.

In some cases, cognitive impairments that require continual observation and prompting to complete daily living tasks are also included among eligibility criteria. Long-term care needs that occur at the onset of a severe disabling condition not only prohibit an individual

from working but also require that they receive daily assistance with basic life activities. For the retired population, where the prevalence of long-term care need is greater, help with daily life is often over and above expenses related to regular retirement living. Unless some provision has been made to pay for those daily living expenses, families' retirement income will be spent at a higher rate, leaving them impoverished in the future.

One major difference between public and private long-term care funding is that most private policies are “dollar denominated,” whereas public programs like Medicaid are “service denominated.” From an actuarial point of view, it is far simpler to design an insurance benefit based on a specific dollar coverage over a fixed period of time (dollar denominated) than it is to adjust for anticipated changes in the mix and prices of different services (service denominated). Private long-term care insurers marketing to those aged 45 to 60 know that they are selling a policy that might not be “activated” for 30 to 40 years. While these policies offer inflation adjustment, they tend not to guarantee a package of services in the future, since the definition of an appropriate service might change, and, historically, health care costs (including long-term care costs) have risen much faster than inflation.

To keep expenses down, those offering *service denominated* policies might need to operate more like managed care companies, contracting with a pool of providers across the areas of the country in which beneficiaries reside. The result might be a reduction in service prices compared to the prices that individuals are charged privately (which is what happens under a dollar-denominated plan, in which the beneficiary is simply reimbursed for money spent on approved long-term care services). However, such a plan would be effective only in markets in which the long-term care insurer has a sufficient volume of beneficiaries such that local providers would be willing to offer a discount on fees for services. On the other hand, *dollar denominated* benefits rarely cover the full daily cost of extensive long-term care service use. An inflation-adjusted policy that pays up to \$100/day for the highest level of need would cover less than half the price of a day of nursing home care at private room rates and would certainly not cover around-the-clock home health care. An alternative way to consider the value of

dollar denominated benefits is to view them as a private sector version of “Cash and Counseling,” in which individuals receive cash benefits that they spend as they so choose.

Whether through universal insurance or a combination insurance/savings scheme, the cost of preparing for the long-term care needs of today’s younger generations requires instituting new programs in which premiums and savings accrue on a much larger scale than they currently do. Doing so constitutes a considerable political and fiscal challenge. And, as discussed in a recent report by the National Academy of Social Insurance (NASI) (Burke, Feder and Van de Water 2005), public funding of long-term care for the current generation of retirees and for the baby boom generation—which has relatively modest savings and retirement assets per capita—may prove even more problematic. Public financing of long-term care has so far been hampered by conflicts between Medicaid and Medicare policies about residential and home- and community-based services. Further, high prices, public distrust, and a lack of uniform standards have limited growth in the private long-term care insurance market, and there is little to suggest the viability of asset recovery and home equity conversa-

tion as a means to meet the long-term care financing challenges ahead.

The nation must engage in a serious discussion about how to pay for long-term care in both the near and long term. Ultimately, the goals should be to institute equitable, comprehensive, and accessible long-term care financing for all Americans. Fundamental to these discussions will be the level of inter- versus intra-generational transfer. Social Security, Medicare, and Medicaid are all “pay-as-you-go” programs, with current generations of workers paying the benefits of today’s elderly and disabled. To add long-term care to these existing entitlements as a largely inter-generationally financed program might be particularly difficult for the majority of workers whose wages have not grown substantially in the past decade and who need to continue to purchase health insurance for their own families. Additional intra-generational distribution of benefits, on the other hand, would mean that the savings of wealthier individuals would necessarily subsidize the long-term care needs of those who were not able to save for their long-term care, for whatever reason. Since this wealthier population is clearly in the minority, the nation must grapple with this issue now.

Chapter III

Empowering Individuals and Families

INDIVIDUALS AND FAMILIES from all walks of life face difficulties in navigating the labyrinth of services and funding sources that constitute long-term care in the United States. These difficulties are reflected in widely publicized testimonials of experts like Jerald Winakur, a geriatrician at the University of Texas, and Robert Kane, a geriatrician and long-term care researcher at the University of Minnesota (Winakur 2005; Kane and West 2005). Although each is an international expert on the clinical needs of disabled persons and on the delivery systems that are supposed to provide that care, both faced untold frustrations as they tried to arrange care for an aging and progressively frail parent shuttled between hospitals and long-term care service providers.

Frustration is also reflected in the numerous untold stories of average Americans trying to overcome impediments to high-quality care for themselves, their parents, or other loved ones. Ironically, in a nation full of caregivers, barriers to identifying even the most basic resources compound the sense of isolation felt by millions of unpaid individuals who provide the bulk of long-term care. Indeed, there is a marked need for educational campaigns aimed at improving consumer knowledge, expectations for quality, and planning for long-term care, as well as a need for care coordination and counseling services that help individuals

“Long-term care is real. But it’s almost a silent crisis that hits a family and, based on our values, we don’t necessarily talk about these things when we go out for dinner, when we socialize. But in your heart, something is not right—because you have a loved one and something is amiss with their care.”

—Former Governor Dirk Kempthorne
of Idaho, Commissioner

and families choose safe and effective options. Expansion of respite and other home- and community-based support would also go a long way toward reducing isolation. In an era of increasingly scarce resources, promotion of information, counseling, and selected support services could have the dramatic effect of helping individuals and families grapple with the challenges of finding decent, affordable care and growing old with dignity.

Informal Caregiving in America

Most long-term care is unpaid, provided by family and friends in the home and community. Nearly 80 percent of adults who receive long-term care at home receive that care exclusively from unpaid caregivers. An additional 14 percent receive both unpaid help and paid, formal care (Thompson 2004). There are currently 44 million unpaid caregivers aged 18 or older who provide care to chronically ill and disabled individuals in 22.9 million American households. Although informal caregivers are diverse, the typical caregiver, a 46-year-old female who has at least some college experience, provides more than 20 hours of care each week to a widowed woman aged 50 or older, usually her mother. The average length of a caregiver's "career" is 4.3 years (National Alliance for Caregiving and AARP 2004). If a value were to be placed on unpaid care in America, it would be in excess of \$257 billion annually (Arno 2002)—more than that spent on paid home care and nursing home services combined.

The National Alliance for Caregiving and AARP (2004) has found that caregiving may range from a few hours per week with a care recipient—handling modest tasks like keeping them company or driving them to appointments—to more than 40 hours per week engaging in physically demanding activities, such as helping a care recipient dress, eat, and go to the bathroom. In addition to such deeply personal tasks, nearly half of family caregivers perform at least one medical task—like bandaging and wound care, operating medical equipment, or administering intravenous medications—for which they, in all likelihood, have little or no formal training (Donelan, et al. 2002). Providing constant supervision for someone with dementia can be especially difficult. Thus, while caregiving poses a minimal burden for some and can, in many cases, be a highly rewarding experience, it can also exact a considerable physical, mental, and emotional toll, as well as one that results in financial hardship, retirement insecurity, a lost job, or other missed opportunities.

Caregiver Support

Most chronically ill and disabled individuals would prefer to live independently in their homes and communities. Although institutions continue to dominate long-term care in most states, state and federal investment in home- and community-based services (HCBS) has increased substantially in recent years, with one-third of Medicaid long-term care spending now being directed toward HCBS and significant growth in Medicaid home health, personal care and waiver participants (Burwell, Sredle, and Eiken 2005; Kitchener, Ng, and Harrington 2005) (Figure 8). This is especially true in Oregon and Washington, states which spend considerably more on HCBS than on institutional care, a policy which serves to empower individuals and families by giving them choices.

The main vehicles for expanding investment in community-based services are federal Medicaid waivers. These waivers grant states the flexibility to expand non-medical, social, and supportive services that allow individuals who would otherwise have qualified for Medicaid-funded institutional care to remain in the community. Between 1999 and 2004, expenditures on these waiver programs increased by 93 percent, from \$11.0 to \$21.2 billion (Burwell, Sredl and Eiken 2005). Between 1999 and 2002, the number of participants grew by more than one-third, from 698,000 to 921,000. Despite growth in the number of waiver programs serving the chronically ill and disabled, 34 states still reported waiting lists totaling 206,427 people in 2004. Further, states exhibit considerable variation in their ability and willingness to fund HCBS, with per capita waiver spending in 2002 ranging from \$8,689 in Arkansas to \$44,271 in Maine (Kitchener, Ng and Harrington 2005).

Beginning January 2007, however, provisions within the DRA will allow states to provide comprehensive HCBS to elderly and disabled Medicaid beneficiaries with incomes up to 150 percent of the poverty level—without going through the waiver approval process (Crowley 2006). In contrast to the restrictions of HCBS waivers, the DRA will allow states to expand coverage beyond those who would have otherwise qualified for institutional care. Further, states need not demonstrate budget neutrality—that costs to the federal government do not exceed the costs

Growth in Medicaid Home- and Community-Based Services Participants, by Program, 1999-2002

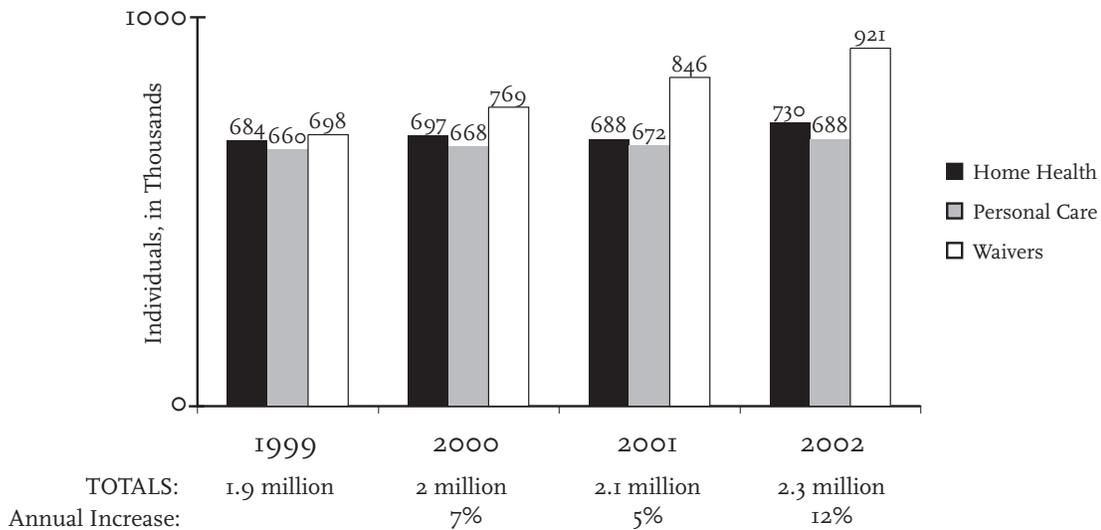


FIGURE 8

Source: Kitchner, Ng, and Harrington (2005)

of institutional services. In contrast to traditional Medicaid, however, states may cap enrollment, maintain waitlists, and elect to provide coverage in only certain areas of the state.

In addition to formal services, several states provide for state reimbursement of informal caregiver services in connection with their waiver and other programs. For example, California's In-Home Supportive Services Program provides reimbursement for personal assistive services provided by family members, and Oregon's Relative Foster Care Program enables certain family caregivers who have loved ones move into their homes qualify as compensable "providers." This is also true of the "Cash and Counseling" program discussed below.

Respite care is particularly important in promoting family stability, preventing out-of-home placements, and reducing abuse and neglect. Forty-six states explicitly provide respite services as part of their Medicaid waivers for aged and disabled beneficiaries (Feinberg et al. 2003). In spite of the fact that "model program" descriptions have been developed and promulgated, studies of the structure and function of states' respite

care programs over the past decade have repeatedly found substantial variation in the operation of these programs (Silberberg 2001).

Recent growth in home- and community-based services has been driven by a 1999 Supreme Court decision, *Olmstead v. L.C.* [527 U.S. 581 (1999)], which concluded that, if disabled individuals could appropriately be treated in the home or community, the use of public funds to care for these individuals in institutional settings violates the Americans with Disabilities Act of 1990 (Allen 2001). In 2001, President Bush issued Executive Order No. 13217, launching the administration's New Freedom Initiative, which outlines the federal government's approach to assisting state and local governments in implementing the *Olmstead* ruling. As part of this initiative, the U.S. Department of Health and Human Services (USDHHS) (2002) pledged to implement programs and demonstrations to eliminate the institutional bias in USDHHS programs and improve the availability and capability of direct care work, including respite and other assistance to families and other unpaid caregivers. Central to the President's initiative is the "Money Follows the Person Demonstration," a program authorized under the DRA, which provides two-year competitive grants for states to increase use of community versus institutional services (Crowley 2006). Incentives include enhanced federal matching under Medicaid for HCBS provided to each person transferred from an institution to the community over a period of 12 months. At just \$1.8 billion over five years, however, funding for the demonstration is limited.

In addition to Medicaid, services supporting individual and family caregivers are funded by the Older Americans Act (OAA). In 2000, Congress amended the OAA to establish the National Family Caregiver Support Program (NFCSP), which calls on states to work in partnership with area agencies on aging (AAAs) and local service providers to develop services that meet caregivers' needs. These include providing information about available services, assistance in gaining access to supportive services, individual counseling, support groups and training, and respite and limited supplemental services (Administration on Aging 2003). Eighteen states provided caregiver support services for the first time as a result of federal funds provided under the NFCSP (Feinberg et al.

"Let's say that I'm 87. And I get up in the middle of the night and I have a stroke and I'm in need of medical attention. I go to the hospital and the judgment is made that I need skilled nursing facility care. Once this has run its course, I am sent home. But sent home to what? My kids no longer live in the area and my brothers and sisters are gone. All I've got is my wife. She's supposed to provide me care in a loving, home-based environment. But she has limited physical capacity. She also doesn't know what the heck to do. Neither does my doctor, though he sends me home with a tray full of medicine—eight different drugs in those little blue boxes, which my wife can barely read. What is going to happen to me? What are we supposed to do?"

—Former Senator Bob Kerrey, Co-Chair

2004). At only \$138.7 million in 2003, however, funding has been modest, and there continues to be considerable interstate variation in the availability of caregiver support programs.

Unpaid assistance does not end at the doorstep of the care recipient. Family and friends play a considerable role in caring for loved ones even after they enter a nursing home or an assisted living facility. In fact, the majority of family caregivers visit their relatives regularly and perform a variety of tasks similar to those performed at home (Yamoto-Mitani, Aneshensel and Levy-Storms 2002). But the burden of performing a variety of new tasks associated with life in an institution also falls on family caregivers, including interacting with facility administration and staff, serving as an advocate and reservoir of knowledge about a loved one's background and history, and participating in care planning and decision-making (Port et al. 2005; Schultz et al. 2004). These are tasks for which family caregivers may or may not have sufficient information to feel confident that they are making the right decisions. The situation is particularly daunting for relatives of the 30 to 60 percent of nursing home residents with Alzheimer's disease or other forms of dementia (Decker

2005; Magaziner et al. 2000). Relatives continue to suffer from the strain associated with family concerns, finances, and the pressures of their own work schedules, problems further compounded by the sense of guilt some feel for having placed their loved one in a nursing facility (Aneshensel et al. 1995; Schultz et al. 2004).

It is clear that greater family involvement is positively associated with clients' health and quality of life, their psychological well-being, the treatment they receive, the way they interact socially, and their general happiness (Chapman, Keating and Eales 2003; Port et al. 2005). But it is not unusual for family members to resent being overlooked or ignored as they try to offer advice or participate in care, and many fear reprisal if they press their concerns too vigorously. This need not be the case, however. Carefully crafted interventions can improve communication, cooperation, and family involvement, with positive effects for family and staff attitudes and possibly resident outcomes (Chapman, Keating and Eales 2003; Jablonski, Reed and Maas 2005; Pillemer et al. 2003). Indeed, enhancing client and family involvement is a critical element of the burgeoning movement to change the culture of long-term care described in Chapter IV.

Information Provision

Although 21 percent of the adult population provides unpaid care (National Alliance for Caregiving and AARP 2004), and 19 to 23 percent of elderly Americans living in their communities suffer from impairments in instrumental or basic life activities (Miller and Weissert 2001), very few are prepared for the eventuality of long-term care when the need arises (see Chapter II). Furthermore, less than half the population would know where to turn for advice or information if they or a family member needed nursing home care (Kaiser Family Foundation 2005). Recognizing the prevailing lack of knowledge and forethought regarding disability, the federal and state governments have recently sought to inform and educate the public on how best to plan for long-term care, manage their conditions, and access available resources.

Perhaps the most widely publicized effort to educate the public has been the “Own Your Future” Long-Term Care Awareness Campaign launched in 2005 by the Centers for Medicare and Medicaid Services (CMS), in cooperation with the states of Arkansas, Idaho, Nevada, New Jersey, and Virginia. The goal of the campaign is to increase awareness of the strengths and limitations of public programs, and to suggest ways to integrate long-term care into retirement planning, including the relevant legal issues, service options, and private long-term financing options. Program activities included a direct mail and media campaign undertaken by each state’s governor and dissemination of a long-term care planning “tool kit” that was requested by eight percent of the 2.1 million individuals contacted between the ages of 50 and 70. CMS plans to expand the program in 2006 to five to ten more states, with the objective of reaching five million households.

A number of states have promoted public/private partnerships that encourage employers to develop corporate eldercare programs for their employees by holding statewide or regional conferences to examine caregiving issues (National Governors’ Association 2004). Both the state and federal governments have also adopted “report cards” intended to help people best decide how to use their long-term care dollars (see Chapter VI). Others have worked to establish nonprofit organizations that inform seniors about health and

“People always talk about how confusing it is and how there’s no place for them to turn for information and guidance. Sometimes we call that ‘navigation,’ and other times we call it ‘single point of entry.’ The point is that there needs to be a place where people can seek help when they or a family member has become frail and needs assistance. But the fact is that the current set-up, with few exceptions, does not provide that place. There needs to be a mechanism to help people understand, and then plan for, what the system is capable of doing when the need arises.”

—Bill Novelli, Commissioner

aging resources in their states. Virginia, for example, has a SeniorNavigator program, which provides information and advice to older people in a variety of areas. Though primarily web-based, SeniorNavigator has a network of volunteers who bring information to those without Internet access. The goal is to provide seniors with enough information to make informed decisions about the services available to them or a loved one. The website includes a 12-question “needs assessment” designed to tailor local programs and services to an individual’s preferences, and it allows visitors to e-mail questions to doctors, geriatric care managers, legal experts, financial advisors, and state and local government officials.

Counseling

Consumer-directed models that allow greater choice in the selection and scheduling of care providers offer a more proactive approach to empowering long-term care recipients and their families. Most consumer-directed programs include counseling services to ensure that individuals and their families are knowledgeable about available resources and how they might be accessed and used. The most prominent example is the “Cash & Counseling” demonstration sponsored by the Robert Wood Johnson Foundation (RWJF), in conjunction with the federal government and the states of Arkansas, Florida, and New Jersey, all of which received Medicaid waivers to create self-directed HCBS programs.

Participants in Cash & Counseling are Medicaid eligible. They are provided with individualized monthly budgets to pay for services that address their specific needs, including hiring workers (even relatives) and, in some cases, purchasing or saving for home modifications, care supplies, and assistive devices. The program also provides counseling to help consumers manage their monthly allowances and responsibilities. Evaluation has yielded positive results with significantly fewer unmet needs and greater satisfaction on the part of consumers, as well as family members, at costs comparable to Medicaid. Self-directed care under Cash & Counseling was also judged at least as safe as agency-directed care, as reflected in reports of disability-related adverse events, health problems, and general health status (Dale et al. 2003a). Furthermore, workers in Cash & Counseling and other consumer-directed programs tend to report levels of stress and satisfaction equal to or more positive than agency-directed workers (Benjamin and Matthias 2004; Dale et al. 2003b). In the wake of the program’s initial success, 12 additional states have received RWJF grants to establish Cash & Counseling programs. Further, the Bush Administration has modeled its Independent Plus initiative—which permits states to develop consumer-directed programs under federal waiver authorities—on the Cash & Counseling program (Crowley 2006). With the recent passage of the DRA, moreover, states may now launch a program based on the Cash & Counseling model without having to seek a Medicaid waiver first; individuals living in provider-run residencies may not qualify, however. Medicaid require-

“In Virginia, we created a web-based tool called SeniorNavigator. It was created as a non-sponsor-driven site in terms of traditional marketing and advertising—so it carries a little bit of a neutral sense, and has been very, very well received in the senior community. We have trained about 10,000 navigators—which could be someone at a church, a library, or a local AAA—so that if someone was making any kind of choice, not just a long-term care choice, there was somebody out there who could help them. It has sure worked well as a way for non-tech savvy seniors to get information from someone that they might trust.”

—Former Governor Mark Warner
of Virginia, Commissioner

ments that programs be statewide and have comparable services do not apply.

The Federal Long-Term Care Insurance Program also incorporates a counseling component. Established by Congress in 2000 for federal employees and retirees and their families, the Federal Long-Term Care Insurance Program now enrolls 200,000—more enrollees than any other long-term care insurance program (U.S. Office of Personnel Management 2005). Under the federal plan, registered nurses assist enrollees in choosing long-term care services, work with them to develop a care plan, and assess, monitor, and reassess options. But

while private care coordination has grown (Health Insurance Association of America 2003), very few people purchase private long-term care insurance policies. Further, to the extent that care coordination is provided, it is unclear how extensively coordinators counsel clients, as opposed to managing utilization to control costs. This is also true of most care coordination in the public sector, including managed care initiatives serving Medicaid/Medicare dually eligible individuals (Miller and Weissert 2004). In light of the utilization and cost management focus of most care coordination, combined with the limited capacity of local government-run area agencies on aging (AAAs) and other local service agencies, there continues to be a marked need to bring information and assistance services to those who need it.

Information and guidance to facilitate smooth transitions across multiple settings of care is especially lacking, resulting in duplication, conflicting or inappropriate recommendations, medication errors, patient and caregiver distress, and higher care costs (Parry et al. 2003). This is particularly true of transitions to and from hospitals and other settings. Hospitals are the principal entry points into long-term care, with approximately one-third of Medicare beneficiaries discharged from hospitals receiving care in post-acute settings (Medicare Payment Advisory Commission 2005b) and 61 percent of all nursing home admissions deriving from hospitals (Gabrel 2000). Nonetheless, hospitals provide limited direction and education about available post-acute options. One major impediment is the current lack of health information technology in long-term care (see Chapter VII). Another major impediment is CMS's interpretation of a federal statute meant to address concerns that some hospitals were intentionally steering patients to home health agencies (HHAs) and skilled nursing facilities (SNFs) owned by the hospital. CMS requires hospitals to provide patients with a full list of Medicare-participating HHAs and SNFs in their geographic area, but bars hospitals from endorsing the quality of providers on the list, or from steering patients toward any particular providers. Although CMS encourages hospitals to turn to its Home Health Compare and Nursing Home Compare websites as sources for this list, CMS also indicates that information from these sites should not be construed as a quality endorsement of any provider (CMS 2004).

“My father-in-law went into the hospital with congestive heart failure. He was discharged on time given the reimbursement policy, but he was discharged too early with transport issues still unresolved. His family was called at 9 a.m. and told to come pick him up. He was not ambulatory, they didn't have a wheelchair, he didn't have his clothes ... They live on the second floor, and his granddaughter had to carry him up two flights of stairs. Two days later he was back in the hospital. Should he have been discharged when he was? Absolutely not. Was there an adequate assessment of readiness for discharge? Absolutely not. Was there an assessment of the ability of his informal caregivers to receive him upon discharge and care for him? Absolutely not. Where was the accountability? Nowhere.”

—Jeanette Takamura, Ph.D., Commissioner

Clearly, conflict of interest is an important concern. It is not desirable to have hospitals preferentially referring patients to nursing homes and HHAs in which they have financial interests. But neither is it desirable for hospitals to provide only a listing of area providers, depriving individuals and families of a critical source of assistance from a trusted source. In general, there should be greater recognition that, during crises, patients and their families need considerable help from hospitals and other resources in making truly informed choices.

A Three-Pronged Strategy

Although comprehensive change is unlikely in today's increasingly unfavorable fiscal landscape, carefully considered incremental adjustments may nonetheless provide a cost-effective means of supporting chronically ill and disabled individuals and their loved ones. This chapter suggests a three-pronged strategy for empowering individuals and families, building on existing efforts in the areas of information, counseling, and caregiver support.

Federal and state officials need to continue their effort to redirect current long-term care spending away from nursing homes and toward respite and other in-home and community support services. There must be a renewed emphasis on educating consumers and families on how to make long-term care choices that best suit their particular needs and circumstances. Indeed, information and counseling is needed to address the prevailing lack of understanding about financing, the role of personal preparation for the risk of needing long-term care services, and the current lack of guidance on how to access needed services, regardless of the ability to pay. The latter is particularly salient as people seek to balance their desire for autonomy with their need to receive safe and effective care. It is clear that we are facing an information, counseling, and service support crisis that we must address if we are to empower individuals and families to meet the challenges of finding appropriate services.

Promoting Physical and Organizational Change

PIONEER ORGANIZATIONS like Meadowlark Hills in Manhattan, Kansas, embrace the notion of overcoming “institutionalism” through congregated small-group homes where residents drive their own lives and are supported by empowered, self-led work teams (Shields 2005). Other reformers embrace similar concepts in the context of continuous quality improvement, innovative end-of-life care, and home- and community-based settings. The common thread is a desire to revolutionize how chronically frail and disabled individuals live and are treated. Collectively known as the “culture change” movement, organizations such as the Pioneer Network, Green House Project, Eden Alternative, Wellspring Institute, and Cooperative Home Care Associates are beginning to transform how long-term care is provided in the United States. But this is only the tip of the innovation iceberg. Increasingly, there are opportunities for long-term care organizations to adopt new technologies, architectures, and workforce processes to enhance the lives of long-term care recipients and the people who care for them. Promoting the further diffusion of innovative technologies and caregiving models that promise a better quality of life for our nation’s elders should become a national priority.

Culture Change

Most novel caregiving models have been developed in the context of nursing homes. Advocates decry nursing homes as oppressive institutional environments entrenched in the biomedical model that treats elders primarily as clinical entities, downplaying their psychosocial and spiritual needs as well as their overall quality of life (Weiner and Ronch 2003). This ethos is reflected in the architecture of traditional nursing homes—long corridors, limited communal space, large dining halls, multiple occupancy rooms, and centralized nursing stations. Like “mini-hospitals,” nursing homes are designed to facilitate the efficient delivery of services in a medical setting. As such, they tend to be organized bureaucratically, leaving little room for decisions to be made by clients or those caring for them on a daily basis. Culture change enthusiasts believe that the key to improvement is restructuring the way care is delivered, implementing systems of care around individuals’ lifestyles, needs, and preferences.

According to the Pioneer Network, an umbrella organization of stakeholders focused on transforming nursing homes into “true homes,” long-term care should be a person-directed service provided by empowered, self-led work teams in household communities supported by value-driven, resource-bearing leadership in an outcome-focused environment. The ultimate goal is to replicate what some refer to as the “rampant normalcy” of everyday life. Nursing home residents are typically told when to get up, eat, and go to bed. Culture change and person-directed care, by contrast, emphasize the importance of asking people about lifelong patterns—do they wake up at 10 a.m. and have toast and coffee and stay up every night to watch Letterman?—and accommodating these patterns and preferences rather than forcing residents to adhere to the routines of the institution.

Ideally, life—both inside and outside an institution—should consist of activities that, according to the World Health Organization and Milbank Memorial

Fund, “ensure that a person who is not fully capable of self-care can maintain the highest possible quality of life, according to his or her individual preferences, with the greatest possible degree of independence, autonomy, participation, personal fulfillment, and human dignity” (2000, p. 6). Adoption of the person-centered approach requires that long-term care providers respond to the values, preferences, and needs of care recipients while incorporating them into the fabric of their local communities (Chapman, Keating and Eales 2003). Where possible, recipients and/or their families should be placed at the center of the caregiving process. Patient participation, client autonomy, and shared decision-making are emphasized (Schoot et al. 2005).

True cultural transformation involves changes in both organizational forms and physical space. At Meadowlark Hills, residents live in a single building organized into six unique households. The households range in size from 13 to 25 residents, each with their own entrance and doorbell. Medication carts, nurses’ stations, and audible buzzers have been replaced by personal medicine cabinets and a system of remote pagers, computers, and monitoring devices. Residents exercise choice regarding most of their daily routines, including when to get up, what to eat and wear, what activities to get involved in, and how to manage their medical conditions. Each household has a dedicated, multidisciplinary staff and leadership team accountable for resident outcomes (Beins 2005).

“At Meadowlark Hills, we realized that part of the sickness of long-term care is not just what we do to residents but also what we do to staff. It’s an assembly-line, industrial-age approach that is ultimately dehumanizing. We recognized that we needed to create self-led teams of people who are closest to the residents and create a household community where the residents and teams build a life together. That’s where all the beauty starts to emerge...”

—Steve Shields, Executive Director,
Meadowlark Hills, 2005

Transforming Architecture

Although the physical plant of nursing homes would ideally be designed to meet the psychosocial and spiritual needs of residents in an environment as home-like as possible, most current architecture is built to accommodate staff efforts to efficiently accomplish tasks—often at the expense of residents’ quality of life. Nursing home construction was typically based on states’ building and fire safety codes for hospitals—resulting in hospital-like facilities that provide limited resident privacy and autonomy in negotiating their environments. Today, organizations like the Society for the Advancement of Gerontological Environments promote better living spaces for elders through education about the therapeutic value of building interiors and exteriors and the surrounding landscape (SAGE Foundation 2005). These organizations emphasize the importance of honoring residents’ needs for privacy, individuality, comfort, and connection with their environment.

There are several barriers to reform. Some barriers reflect a tension with federal regulations, particularly safety codes, that promote uncluttered spaces and have been applied more vigorously following multiple-death nursing homes fires. Other barriers relate to state fiscal control over Medicaid spending. Medicaid rules constrain the number of private rooms by limiting their use by Medicaid residents, and they may also limit the amount of social space available. Medicaid reimbursement policies have, however, generally supported cost growth in excess of inflation and would likely support more social space if administrators chose to allocate money for this purpose.

Others barriers relate to the challenge of raising capital funds to build or modify facilities to better reflect the resident-centered paradigm. These barriers will be increasingly salient given the age of nursing homes in the U.S., many of which have already been written off in terms of depreciation and will soon need to be replaced. As the current stock ages out of use, there is a need for incentives that promote construction of resident-friendly facilities.

“Look, we have to have something that is more in accord with human dignity, with individuality, with a reciprocity between the people that provide the formal care—the paid people—and the people that are being cared in more intimate kinds of circumstances where the physical environment is pleasant, where there is some opportunity for individuals to get up when they want, where there is room for individual expression.”

—Monsignor Father Charles Fahey,
Commissioner

Transforming Caregiving

Despite restrictions posed by the architectural configuration of most existing facilities, pioneering nursing homes throughout the country have begun the process of transforming themselves into “real homes.” These pioneers are finding that, although the physical plan is important, it does not ensure the requisite organizational and value changes necessary for deep, long-lasting transformation. Most culture change initiatives, therefore, emphasize—above all else—the way the caregiving process is organized, and how certain management practices distinguish the culture of nursing homes and home care agencies with lower turnover and higher-quality care from those with higher turnover and lower-quality care. Effective leadership and management are critical, along with a work environment that values and respects direct care workers and the people they care for—and gives them decision-making authority (Buelow, Winburn and Hutcherson 1999; Eaton 2002; Flynn 2005; Rantz et al. 2004).

For example, there are many benefits of “primary-assignment” policies that encourage staff to work consistently with the same residents. Ninety percent of nursing homes rotate staff from one group of residents to another after a period of time, making it difficult for staff to learn about a particular resident’s needs and personal preferences (Farrell 2005a). This is also a problem in home care. A recent home care study identified several attributes necessary to ensure continuity of care, including continuous, uninterrupted service delivery; consistent knowledge and skills; ongoing, accurate observation; trusting client-caregiver relationships; and consistent timing of service delivery (Woodward et al. 2004).

There are several reasons that long-term care organizations do not engage in primary assignment, including a prevailing focus on workers’ functional utility, irrespective of who performs tasks and for whom those tasks are performed. The current practice also facilitates scheduling and enables administrators to rapidly plug holes when staff problems arise.

Primary-assignment, by contrast, promotes greater client-caregiver bonding, thereby increasing caregiver satisfaction and providing the foundations for person-centered care—with positive ramifications for quality of life and client outcomes (Burgio et al. 2004;

“There is a need to identify the best places in the country and why they are the best and then to codify that information in a way that allows you to say, ‘This is the standard toward which people ought to work, and these are the lessons that tell us how we should design our public policy.’”

—Former Speaker Newt Gingrich, Co-Chair

Goldman et al. 1998). There is also considerable interest in self-managed work teams, which have been demonstrated to lower absenteeism and turnover and improve decision-making, job satisfaction, and performance in manufacturing settings (Barry, Brannon, and Mor 2005; Yeats et al. 2004).

Experience with culture change models suggests that there can be a significant and sustained transformation in long-term care organization and the quality of life it provides.

Towards Culture Change in Nursing Homes

The culture change movement first took root during the 1970s. It began as an effort to promote quality of life through a client-focused, service approach to care. Perhaps the most broadly implemented culture change model is the Eden Alternative, which began in 1992 as an effort to improve care in a single 80-bed upstate New York nursing facility and has since spread to more than 200 facilities in every U.S. state, Europe, Asia, New Zealand, and Australia (Thomas 2004). More than 7,000 “Eden Associates” have been trained under the supervision of Dr. William Thomas, the model’s developer. The primary goal of Eden is to make nursing homes more humane, varied, and spontaneous. Strategies include introducing companion animals and indoor plants and gardens and encouraging frequent visits by children (Thomas 2003). Eden also de-emphasizes top-down bureaucratic authority by placing as much decision-making responsibility as possible in the hands of residents and their caregivers. Although one study reported no beneficial effects of Eden after one year of implementation in a single facility (Coleman et al. 2002), others suggest that Eden may be associated with lower levels of boredom and helplessness, enhanced family satisfaction, and reductions in behavioral incidents, pressure sores, restraints, staff absenteeism and turnover, and employee injuries (Bergman-Evans 2004; Rosher and Robinson 2005; Thomas 2004).

Dr. Thomas also developed the Green House Project, which fundamentally redesigns the foundational philosophy, architecture, and organizational structure of traditional facilities. Like Meadowlark Hills, this model transforms nursing homes from a single large building into multiple self-contained residencies for eight to 10 elders—including private rooms and bathrooms and a warm, inviting communal space with a hearth, dining room, and full kitchen. Residents control their own schedules, including sleeping, eating, and other activities. Direct care workers are provided with hours of additional training and empowered to manage themselves, with a visiting support team providing necessary clinical services. Green Houses are skilled nursing home facilities operating under traditional state regulations, with a licensed nursing home administrator accountable for all outcomes.

In 2003, four Green Houses were built in Tupelo, Mississippi, as part of a pilot project funded by the Robert Wood Johnson Foundation. The Green Houses are being evaluated by researchers at the University of Minnesota. Preliminary results indicate that, compared to the control group, Green House residents experienced less functional decline, depression, incontinence, and inappropriate use of antipsychotic medications, as well as a greater quality of life along several dimensions, including physical comfort, privacy, dignity, friendship, safety, foods, spiritual needs, choice, and control. Family members reported greater satisfaction with their relative’s life and care. Staff reported knowing residents better and feeling more empowered to assist them. They also reported greater job satisfaction, and staff retention was much higher, with only a 10 percent turnover rate over two years (Rabig 2005). Twenty additional Green House models are now in the process of being implemented in 17 states. In urban areas, however, capital expenses—land purchase and demolition/renovation costs—may pose significant barriers to adoption.

Another widely cited initiative is the Wellspring Model, first adopted in 1994 by 11 facilities in northeastern Wisconsin. Since then, 80 additional facilities in six states and the District of Columbia have engaged in the two-year implementation process required for replication. Essentially, Wellspring provides a mechanism for embedding a resident-centered, continuous quality-improvement process into nursing homes. The goal is to improve skills, knowledge, and collaboration among staff while fostering accountability to improve care outcomes (Bowers 2004). Central to Wellspring are alliances of eight to 10 facilities that work together to share insights about how to improve quality. An advanced practice nurse develops training materials and teaches staff at each of the facilities how to apply nationally recognized clinical guidelines for general clinical and organizational assessment, leadership, and six specific clinical areas. At the facility level, multidisciplinary “care resource teams” receive training and are responsible for teaching other staff how to improve care in their areas of expertise (Reinhard and Stone 2001). A 15-month evaluation found that, compared to other Wisconsin nursing homes, facilities in the original Wellspring Model experienced lower costs and significantly fewer major deficiencies in the federal

survey process. However, using other data, there was no clear evidence of improvement in clinical outcomes, although staff took a more proactive approach to resident care and qualitative data revealed better staff-resident interaction and improved quality of life (Stone et al. 2002).

The nation's Quality Improvement Organizations (QIOs), charged by CMS to improve the quality of medical care for Medicare beneficiaries, have also promoted culture change. Not only have they encouraged wider adoption of evidence-based quality-improvement approaches, especially among the 2,500 nursing homes that have volunteered for intensive assistance from their local/state QIOs, but they have also promoted transformational change among a subset of these facilities. Rather than the all-encompassing approach of models such as Wellspring, Eden, or Green House, however, the QIO responsible for initiatives in long-term care—Quality Partners of Rhode Island—has taken an incremental approach, in which specific culture change practices are piloted on a limited basis before being implemented more widely within organizations. This strategy is reflected in two national demonstrations, the Person-Directed Care (PDC) pilot and Workforce Retention (WR) pilot, both of which ran from October 2004 through September 2005. Each intervention integrated quality improvement principles with relationship-building skills taught through interactive, experiential learning. Residents in both studies experienced reductions in pain and physical restraints. Nursing homes participating in the WR study experienced lower rates of staff turnover as well as a decline in delirium among the post-acute segments of their resident populations (Farrell 2005b; Quality Partners of Rhode Island 2005).

Toward Culture Change in Home Care

Although culture change models have primarily focused on the residential side of the long-term care equation, some of their basic principles have also begun to permeate the home- and community-based sector. This is exemplified by a growing emphasis on person-centered care, including the Cash & Counseling demonstration and other consumer-directed models (see Chapter III). Indeed, because people needing long-term care tend to be increasingly lower-functioning and in worse health as they move from traditional community care into assisted living and then into nursing homes, care recipients living at home or in assisted living may be better equipped cognitively, emotionally, and physically to direct their care teams than those residing in institutions (McCormick and Chulis 2003).

In addition to the growing prominence of person- and consumer-directed care, culture change is reflected in the adoption of evidence-based quality improvement in home care. Examples include two demonstrations implemented in the State of Indiana, the Normative Treatment Planning (NTP) program and the Client Feedback System (CFS) program (Kinney et al. 2003). Both programs served clients enrolled in that state's case management and/or Medicaid HCBS waiver programs. Whereas NTP provides for standardized assessment of clients' needs and regular collection of data on needs met, CFS provides vendors with systematic feedback on client perceptions of home care services. Evaluation took place between 1995 and 1997. Compared to the control group, results reveal fewer unmet needs among clients enrolled in NTP and greater satisfaction among clients enrolled in NTP or CFS. However, clients enrolled in both programs did not experience significantly better functional performance outcomes.

More comprehensive culture change efforts in home care generally focus on improving the work environments of long-term care workers; by creating a more stable workforce, these efforts are intended to improve the quality of patient care. Often cited is Cooperative Home Care Associates (CHCA), a worker-owned home health agency based in New York's South Bronx. CHCA employs more than 800 workers, mostly minority women and former welfare recipients.

Through comprehensive assessment and screening and partnerships with human service organizations, CHCA identifies those individuals most likely to succeed as direct care workers. Prospective aides receive twice the entry-level training of most home health aides, training that emphasizes active learning, critical thinking, problem solving, cooperative team-building and on-the-job experience. Employees receive access to full-time employment counselors to help them overcome obstacles to on-the-job success. Managers and supervisory staff are trained in a coaching style of management which, while holding workers accountable, offers support in resolving performance issues. There are also opportunities for career advancement, leadership development, and working participation in agency decisions. CHCA has established three levels of home health aides, with each successive level associated with additional training and higher wages. There are also opportunities to advance to positions within administration and training, and several programs have been established to help aides advance to other occupations (e.g., nursing). Approximately 80 percent of CHCA's employees share in ownership, with the majority of board members being elected from among direct care staff (Inserra, Conway and Rodat 2002; Powell 2006; Stone 2004).

Though still low, at \$6.40 to \$8.00 per hour, wages at CHCA are \$2.00 an hour higher than the average for New York home care agencies. Aides typically work 36-hour work weeks and receive health insurance, retirement, vacation, and annual dividend benefits. Between August 2001 and August 2002, turnover at CHCA stood at only 22 percent (Powell 2006), less than the 40 to 60 percent recorded elsewhere in the home health industry (Paraprofessional Healthcare Institute 2005). CHCA's workforce has doubled in size since 1998, but 25 percent of CHCA's workforce has been with the agency for five years or more. Aides at CHCA report feeling respected and valued for their work. The agency has also developed a reputation for being reliable, client-centered, and compassionate. Lessons learned have been shared, with varying degrees of success, with home care agencies in other states (Inserra, Conway and Rodat 2002; Powell 2006; Stone 2004).

“It seems to me that in long-term care we’re focusing on safety, food, and shelter, and not focusing nearly enough on things that actually make us human—dignity, privacy, responsibility, all of those things. And when we think about quality we really need to think about how people live their lives and what their lives are like. Right now, long-term care is provider-centered and funding source-centered rather than person-centered. Culture change needs to take place throughout the system, not just in nursing homes.”

—Bill Novelli, Commissioner

Toward Innovative Palliative and End-of-Life Care

Long-term care includes both supportive and medical services, and a formidable challenge lies in determining how effectively “medicalized” post-acute, palliative, and end-of-life care can be delivered. Hospice services are provided by home health agencies as well as by hospice-only providers. According to the National Home and Hospice Care Survey, there were 621,100 discharges from hospice care in 2000, with 61 percent residing in a private or semiprivate residences during their episode of care and 35 percent residing in an inpatient health care facility (Haupt 2003). Although experts recommend at least 30 days of hospice care to achieve maximum benefit (Travis et al. 2002), most people do not receive sufficient hospice care; this appears to be more of a problem for people residing in institutions than for those in home- and community-based settings. Forty percent of private/semi-private discharges received 30 days or more of care, compared to only 30 percent of institutionalized discharges. Further, the median length of service for non-institutionalized discharges (20.6 days) exceeded that of discharges from health care facilities (6.4 days) (Haupt 2003). Thus, while there is certainly room for greater home health-hospice collaboration (Hanley 2004), the need for more effective integration of hospice services into nursing homes and other health care institutions appears to be more pressing. Indeed, family members report greater concern for end-of-life care received by loved ones in a nursing home or hospital than at home with hospice (Teno et al. 2004).

Since the proportion of deaths occurring in nursing homes has been rising for over a decade, the recent emergence of hospice services in nursing homes is an especially important innovation. In 2001, 23 percent of non-traumatic deaths occurred in nursing homes (Teno 2004). Among those aged 65 or older, 28 percent of all non-traumatic deaths occurred there, including 66.9 percent of dementia-related deaths (Mitchell et al. 2005). This percentage is likely to increase in the future as the population ages and nursing homes serve an increasingly debilitated mix of patients. Nursing homes have a poor record of providing high quality care to dying patients (Wetle et al. 2004), and unless nursing homes embrace hospice care and a culture of effective and humanistic palliative care, the end of life is going to be

extremely difficult for many people.

Nursing homes are generalists. They serve a general population of people who are frail and older— some are dying, some are quite stable in their frailty for long periods, and, depending on the nursing home, some are undergoing rehabilitation. A growing number of facilities are working to develop their own expertise in hospice and palliative care, but many more are forming partnerships with hospice programs to provide better experiences for those at the end of life. According to analysis of data from the Online Survey, Certification, and Reporting System (OSCAR), the percentage of nursing homes contracting with hospice programs doubled, from 30 percent to more than 60 percent, between 1997 and 2004 (Figure 9)—though there is considerable variation both within and across states.

Ideally, hospice coordinates care while providing space for patients and their families to transition from this life to the next. The goal is to meet the three quality parameters of the dying experience: safe and comfortable dying, effective life closure, and setting up a process for caring, grieving, and bereavement of those left behind (National Hospice and Palliative Care Organization 2006). Indeed, evidence shows that hospice care provides a higher-quality model of care for nursing home residents at the end of life by more effectively managing patients’ symptoms and by reducing hospital transfers in the last weeks of life. Family members of persons who have died in nursing homes have perceived improvements in care after hospice enrollment, and nursing home staff and administrators report that hospice helps them provide more individualized care to dying patients. Interestingly, non-hospice residents in nursing homes with higher proportions of hospice residents also experience fewer hospitalizations and more frequent pain assessment, perhaps because greater hospice penetration influences the culture and caregiving philosophy of an entire facility. Medicare and Medicaid expenditures in the last month of life, when most residents enroll in hospice, are not significantly higher when hospice care is provided to nursing home residents, and may even be lower for short-stay residents (Miller, Gozalo and Mor 2001; Miller, Mor and Teno 2003; Miller et al. 2004).

Despite the marked increase in nursing homes contracting with hospice programs and the positive impact of hospice on care quality and cost, there are

Percentage of Nursing Homes that Contract with Hospice

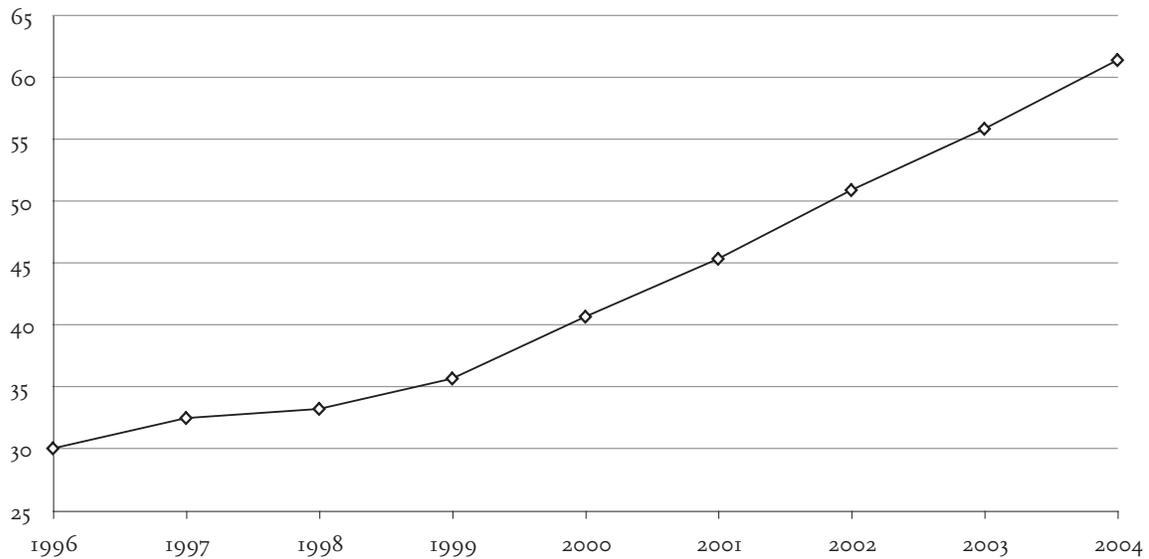


FIGURE 9

Source: Online Survey, Certification, and Reporting (OSCAR), 1996-2004

several regulatory barriers to further nursing home-hospice integration. Because nursing home regulations and reimbursement emphasize provision of restorative and rehabilitative care, nursing homes may be reluctant to embrace palliative care. Residents who are deteriorating will at some point look sicker. Unless there is a note in the care plan indicating palliative and hospice care, the facility can be penalized for physiological deterioration—even though the primary goal has shifted from attainment of the highest practicable well-being to management of end-of-life needs (Miller and Mor 2004; Miller, Teno and Mor 2004).

Medicare's hospice benefit also requires certification of a six-month prognosis by two physicians, though accurately predicting life expectancy for persons dying with diseases other than cancer is difficult at best. Because physicians are reluctant to make this determination, and because physicians, patients, and families are often reluctant to give up hope, the number of days of hospice service received by the average patient is quite short, often less than a week. Educational efforts directed toward physicians about the "looseness" of the six-month policy are associated

with increased lengths of stay in hospice. Lengths of stay in hospice are also longer in the non-Medicare world, where patients, families, and doctors need not stipulate a six-month prognosis (Miller and Mor 2004; Miller, Teno and Mor 2004).

Current Medicare regulations prevent nursing home residents from simultaneously choosing Medicare hospice and skilled nursing facility (SNF) benefits, providing a financial disincentive for private pay residents to choose hospice—since they would then be required to pay for nursing home services out-of-pocket. There are also financial disincentives for nursing homes serving patients simultaneously enrolled in Medicare and Medicaid, as referral to hospice would require nursing homes to forego higher Medicare SNF per diem payments in favor of lower Medicaid nursing home per diem rates. Further, there are any number of additional technical and administrative barriers to closer hospice-nursing home relationships (Miller and Mor 2004; Miller, Teno and Mor 2004). In order to ensure dignity, respect, and comfort for dying nursing home residents, disincentives for further hospice and nursing home collaboration must be overcome.

Toward Innovative Adaptive Technology and Assistance

There are many innovations with which residential and home- and community-based long-term care providers have experimented: adoption of special care units, establishment of relationships with hospitals and other referral sources, computerization of resident assessments, investment in quality monitoring and quality improvement activities, innovative training and job enhancement programs, contracting with hospice providers, and, of course, adoption of comprehensive changes in organizational culture. Nevertheless, both residential and home- and community-based long-term care are still deficient in the application of innovative technologies and even in the use of basic technology—like a new cane, a new walker, or a microwave oven. In general, there needs to be increased adoption of simple assistive technologies and environmental designs to enhance an individual's independence and greater investment in selected therapeutic technologies that foster a return to independent functioning.

Research suggests that the proportion of the aged population that is disabled, requiring assistance with daily personal and home tasks, has been declining over the last several decades. This decline is partially related to use of mobility aides, home technologies like microwave ovens, and the rise of environmental adaptations like elevators, bars in the bath, and even emergency response systems (Cutler 2001; Naik and Gill 2005; Wolf, et al. 2003). We know that each year more than 10 million disabled older adults living in the community receive more than 30 hours per week of assistance with daily activities—and that most of that help is provided by family members (Laplante, Harrington, and Kang 2002). Canes, walkers, and other mobility aides reduce the need for family members to assist with mobility within and outside the home and expand the life space of frail elders (Hoenig, Taylor, and Sloan 2003). Yet fewer than 20 percent of those individuals use mobility aides and other devices (Agree and Freedman 2003; Allen, Resnik, and Roy 2006; Taylor and Hoenig 2004). Further, environmental adaptations like bars in the bath are present in fewer than half of homes in which disabled elders reside; individuals without bars in the bath are more likely to

report difficulty bathing and are far more likely to require human assistance (Naik and Gill 2005).

It may well be that few elderly individuals realize that Medicare or Medicaid typically provides coverage for mobility aides or appreciate the effect that these aides could have on their lives and independence. Furthermore, no insurer—public or private—adequately covers home modifications or other potentially helpful assistive technologies. Whereas durable medical equipment—such as wheelchairs, orthotics, and prosthetics—are well-covered by Medicare, the program provides only limited coverage for technologies assisting with activities of daily living (ADLs) (e.g., grabbers, button hooks, adaptive utensils, elevated commodes, chair-lifts) and no coverage for eyeglasses, hearing aides, home modifications, and other assistive devices (Freiman, et al. 2006). Moreover, coverage of assistive technologies varies considerably under state Medicaid programs. Most provide coverage for orthotics, prosthetics, and eyeglasses; slightly fewer (~80 percent) cover technologies assisting with ADLs and personal mobility, and even fewer (~60 percent) for hearing aides and augmentative communication devices such as voice synthesizers, Braille word processors, and personal emergency response systems. Beyond the occasional waiver program, however, most states do not provide coverage for home modifications. Further, private health insurers often do not reimburse for assistive devices unless they are deemed “medically” necessary—even though substantial evidence exists that such devices are effective in delaying functional dependence.

In addition to simple assistive devices, older Americans have been among the primary beneficiaries of substantial advances in advanced therapeutic technologies and treatments over the last several decades. Cataracts are removed without hospital stays, hip and knee replacements transform patients with pain and impairment into non-disabled individuals, and new drug and surgical treatments for heart disease have reduced associated mortality and morbidity in the elderly population (Cutler 2001). These advances may have contributed to the reduced level of disability among the aged, and there are numerous opportunities for further advancement that will have a material impact on the lives of older people who require long-term support and assistance at home or in institutional

settings. Among the most promising areas of technological and treatment innovation are labor-saving robotics designed to enhance the provision of rehabilitative services.

Innovations in rehabilitation could make the difference between an older patient regaining his or her prior functioning after a stroke or fracture or being told that he or she is not making enough “progress” and therefore is no longer covered by Medicare. A robotic therapy machine, for example, has been designed especially for stroke victims. The machine provides patients a customized routine of exercises that is actually guided by the robot, allowing many more repetitions of the exercise than typical. Preliminary results suggest that chronic pain is decreased and strength and balance improves with use of the therapy machine (Thompson 2005). Other advances are likely to prolong independence, whether robotic spoons that make it easier for the frail and disabled to feed themselves, power suits that help infirm individuals move about or lift heavy items, or machines that facilitate cooking, vacuuming, and other household activities (Japan’s Humanoid Robots Better Than People 2005). These and other innovations will increasingly become available. It is critical that long-term care providers, the frail older patient, and families be in a position to take advantage.

Innovation as Investment

Innovation—whether comprehensive changes in organizational culture, caregiving, architecture, end-of-life care, or adaptive technology and assistance—is positively correlated with quality of care in a variety of areas. Less widely acknowledged is the evidence that innovative organizations tend to perform better than less innovative ones. According to one study, for example, implementation of continuous quality improvement tended to be greater in nursing homes with organizational cultures emphasizing innovation and teamwork (Berlowitz et al. 2003); in another study, lower-quality nursing homes with higher staff turnover had per resident day costs \$13.58 higher than those of higher-quality nursing homes with lower turnover (Rantz et al. 2004). In fact, nursing homes that routinely adopt innovations and make choices to diversify and specialize are more likely to do well across a variety of areas—they maintain higher occupancy levels, attract a more lucrative mix of patients, receive fewer deficiencies during the federal inspection process, and experience a lower likelihood of being terminated from Medicare and Medicaid (Mor et al. 2005; Zinn et al. 2005). In short, there are significant “returns on investment” to long-term care providers that embrace innovation, which, in turn, affects the quality of care and quality of life of care recipients. There needs to be both increased recognition of these “returns” and further encouragement of the innovation and culture change efforts necessary to procure them.

Investing in the Long-Term Care Workforce

A WELL-TRAINED, STABLE WORKFORCE— with professionals and paraprofessionals such as certified nurse assistants, home health aides, personal assistants, licensed practical nurses, registered nurses, nurse supervisors, physicians, social workers, pharmacists, administrators and therapists specializing in care for the chronically ill and disabled—is a prerequisite for quality long-term care. But for every person who enthusiastically embraces a rewarding career in long-term care, countless others lack the necessary incentives and opportunities to do so. Although this is especially true of lesser-skilled workers—for whom the combination of low wages, insufficient benefits, inadequate training, heavy workloads, and associated stigma conspire to make recruitment and retention a challenge—it is also true of nurses, physicians, and others who prescribe services and supervise direct care staff.

A Profile of the Long-Term Care Workforce

According to the U.S. Bureau of Labor Statistics (USBLS), there were 3.85 million individuals employed in long-term care in 2003, 57 percent of whom delivered direct care, including 545,690 RNs and LPNs and 1.65 million nurse aides, home health aides, and personal care workers (American Health Care Association 2004). Compared to the workforce in general, nurse aides working in long-term care (nursing homes, home health) are more likely to be female (90.9 percent, 89.2 percent), non-white (43.3, 51.4), and unmarried (60.6, 56.4), to have a high school education or less (72.6, 62.1), and to have children at home (56.3, 51.1). Nearly 50 percent have incomes below 200 percent of the federal poverty level. Approximately half are between the ages of 25 and 44 (U.S. General Accounting Office 2001). On average, home care aides tend to be older than nursing homes aides (46.2 vs. 38.0). Compared to nursing home aides, home care aides are also more likely to be Hispanic (15.9 v. 7.8 percent) and to be foreign-born and/or non-U.S. citizens (23.7 v. 13.8 percent).

The USBLS estimates that in 2003 there were 170,880 RNs and LPNs and 567,150 paraprofessional staff, including 255,370 home health aides and 269,860 personal and home care aides, employed in home-based service (American Health Care Association 2004). Because a significant proportion of home-based aides are hired privately, however, USBLS likely underestimates the number of home care workers (Stone 2004). This explains, in part, why one recently published study using data from the 2000 Census and including workers employed by both private households and home care agencies resulted in the figure of 788,149, significantly higher than those previously published (Montgomery et al. 2005). Regardless of the exact figure, the demand for home care workers has grown in light of consumer preferences for increased public funding for HCBS and socioeconomic and demographic trends that

favor a more consumer-driven market (Wright 2005). USBLS (2005) projects that, between 2004 and 2014, home health aides will be the fastest-growing U.S. occupation, at an estimated growth rate of 56 percent; personal and home care aides, at 41 percent, are projected to be the fourth fastest. The numbers of registered nurses and nursing aides/orderlies/attendants are expected to grow by 29.4 percent and 22.3 percent, respectively, during the same time period.

More comprehensive data is available on staffing in nursing homes, where 80 to 90 percent of hands-on care is provided by nurse aides. Analysis of OSCAR data indicates that the numbers of RNs and LPNs working in nursing homes remained steady at about 100,000 and 200,000 full-time-equivalent employees (FTEs), respectively, between 1992 and 2004; the number of CNAs declined from 700,000 to 600,000 FTEs. The number of residents, by contrast, increased from 1.28 million to 1.63 million between 1977 and 1999, and the number of beds per facility increased from 79 to 105 (Decker 2005). This growth in utilization has been accompanied by greater acuity among residents, with the proportion of residents aged 85 or over increasing from 34.8 percent to 46.5 percent between 1977 and 1999, and the proportion able to independently perform basic life activities (eating, walking, dressing, and bathing) declining during those years (from 66.8 to 52.8 percent, 32.9 to 21.1 percent, 29.6 to 12.9 percent, and 13.0 to 5.6 percent, respectively) (Decker 2005). Thus, as the number of CNAs has declined, workloads and residents' social and medical complexity have grown significantly.

Staffing Levels & Quality

Clearly, providers must have enough well-trained staff to perform the tasks necessary to respond to every client's needs. Analysis of OSCAR data indicates that total staff hours per resident per day in 2004 averaged 3.6—approximately 0.5 for RNs, 0.8 for LPNs, and 2.3 for CNAs. Federal law requires a minimum of eight hours per day of RN services and 24 hours per day of licensed nursing service in a certified nursing facility. Although 36 states have adopted their own nursing facility staffing levels, no staff-to-resident ratios or hours per resident per day requirements have been established by the federal government (Tilly et al. 2003).

Total staff hours in many nursing homes are below recommended levels (Figure 10). Nearly 30 percent of nursing homes average fewer than 2.75 nursing hours per patient per day, the minimum recommended by the federal government (CMS 2002). Fewer than 10 percent average more than 4.55 hours per patient per day, the level favored by many experts in the field (Harrington et al. 2000). There is also dramatic interstate variation in staffing levels. According to OSCAR, more than half the nursing homes in seven states—Missouri, Oklahoma, Kansas, Iowa, Illinois, Texas, and New Mexico—do not meet minimum federally recommended standards. Forty percent of nursing homes nationwide would need to increase total staffing levels to meet CMS's preferred minimum standards, and 95 percent would need to increase total staffing levels to meet the levels preferred by advocates.

Currently, the federal government lacks a process for collecting and monitoring accurate staffing data in nursing homes and among home care providers. There is considerable heterogeneity in residents' social and clinical needs from facility to facility, and uniform staffing ratios that do not take such variation into consideration might not be appropriate.

Research has consistently demonstrated a relationship between staffing and quality of care in nursing homes. Better staffing has been associated with higher resident survival rates and functional status; fewer pressures sores and infections; less physical restraint, catheterization, antibiotic use, and weight loss; and lower hospitalization rates. Better staffing also leads to lower worker injury and litigation rates and less stressful conditions, so that physical and psychological abuse

Percentage of Nursing Homes Meeting Various Recommended Minimum Total Staff Levels, Hours Per Resident Per Day (HPRD), 1992-2004

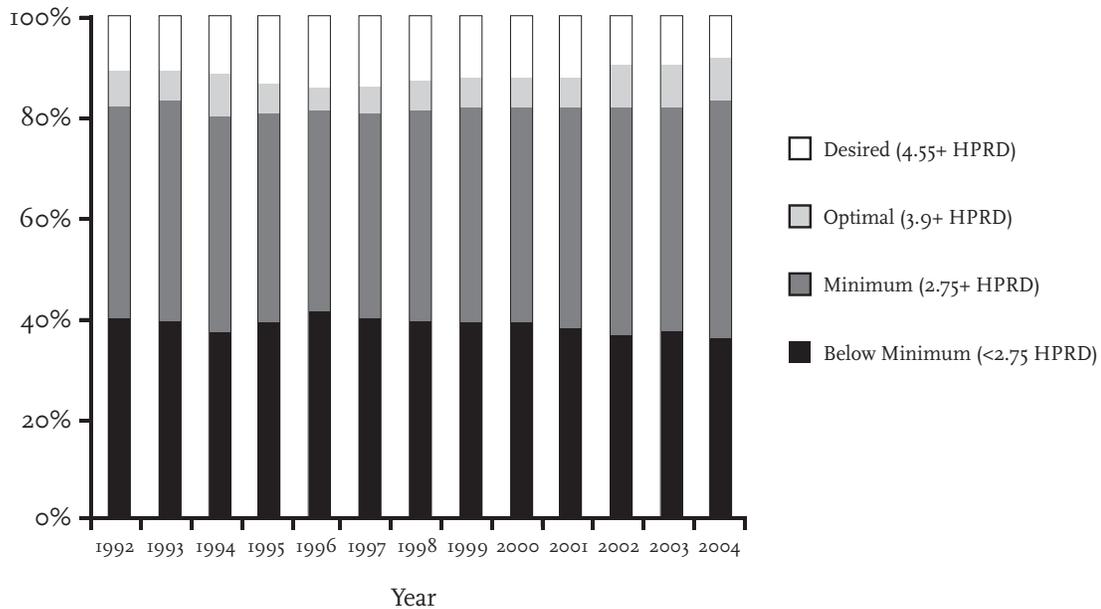


FIGURE 10

Source: Online Survey, Certification, and Reporting (OSCAR), 1996-2004

may also be less likely (Castle and Engberg 2005; CMS 2002; Institute of Medicine 2001, 2003; Schnelle, et al. 2004). Although there is little empirical evidence about the relationship between staffing and quality of care in home care, Stone (2004, p. 525) observes that “anecdotes and qualitative studies suggest that problems with attracting and retraining direct care workers translate into poorer quality and/or unsafe care, major disruptions in continuity of care, and reduced access to care.” Without sufficient staff, home care agencies may not have enough aides to send out, let alone be able to provide clients with the same good worker daily. This increases pressure on family caregivers, who already provide most care to frail and disabled individuals living in the community (Stone 2004). It may also lead individuals and families to choose residential care options even if those options are not among their preferred choices.

Available evidence also suggests that the mix of staff may affect quality. Frail residents in nursing homes that employ advanced practice geriatric nurse specialists experience fewer hospital readmissions and nursing home-to-hospital transfers (Intrator, Zinn and

Percentage of Freestanding Nursing Homes Employing 5% or More Contract Nurses, 2004

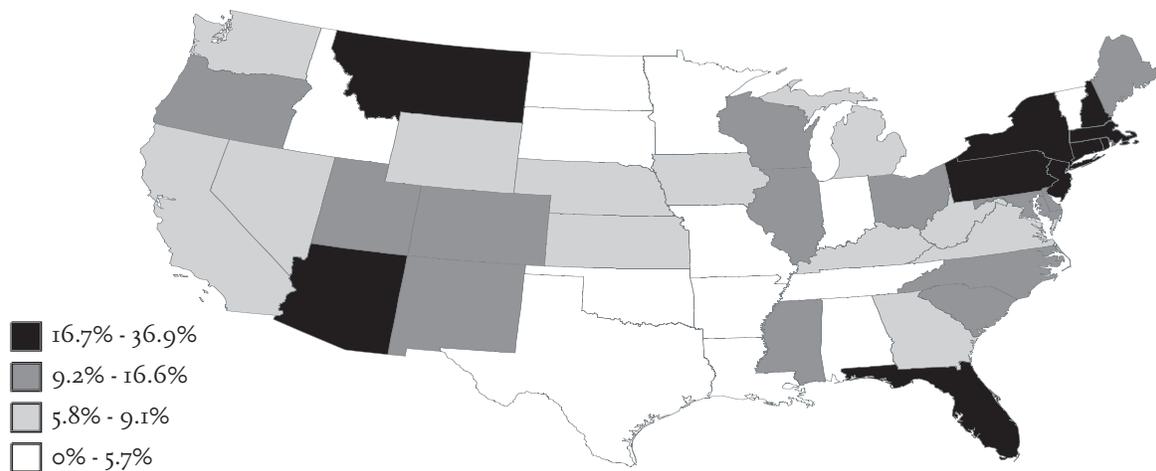


FIGURE 11

Source: Online Survey, Certification, and Reporting (OSCAR), 1996-2004

Mor 2004). However, these staff resources are relatively rare. Indeed, the nursing shortage has translated into increased use of contract nurses, which undermines continuity of patient care. Analysis of OSCAR data indicates that the percentage of nursing homes using five percent or more contract nurses doubled between 1997 and 2004, from five to 10 percent for RNs and seven to 14 percent for LPNs, respectively (Figure 11). There is evidence to suggest that this level of use of contract nurses is associated with poorer quality care as measured using intra-state deficiency rankings (Bourbonniere, et al. 2006). Leadership with special training and certification might make a difference as well. Although there are currently only 500 active certified nursing home administrators, facilities administered by such professionals perform better in terms of the number and severity of deficiencies and quality outcomes (American College of Health Care Administrators 2005). There is also limited evidence to suggest that a relationship may exist between the quality of home care workers and clinical, functional, and lifestyle outcomes of consumers (Stone 2004).

Staff turnover in long-term care is particularly problematic. Annual turnover rates in home care range from 40 to 60 percent (Paraprofessional Healthcare Institute 2005). Annual turnover rates in nursing homes approach 50 percent for most staff categories and, depending on the tightness of the labor market, may exceed 100 percent in certain areas as positions must often be filled multiple times during a year. At 71.1 percent in 2002, turnover is especially high among CNAs (Decker et al. 2003). Turnover in nursing home leadership is equally problematic; half of directors of nursing, staff RNs, and LPNs were replaced in 2002, as were 35.5 percent of administrative RNs. Recent estimates also place turnover among administrators at somewhere between 40 and 43 percent (Castle 2005).

Turnover is quite varied across regions. In New Jersey, New York, and Pennsylvania, CNA turnover was estimated to be 45.7 percent in 2002, while in Arkansas, Louisiana, Oklahoma, and Texas, the rate exceeded 100 percent (Decker et al. 2003). The volume of vacancies in nursing homes is also high, with an estimated 96,000 FTE vacant positions in 2002 (Decker et al. 2003). Approximately 52,000 of these vacancies were for CNA positions, with an additional 13,900 and 25,100 for RN and LPN positions, respectively. Vacancy rates were especially high among staff RNs (15.0 percent) and LPNs (13.2 percent) and somewhat lower for CNAs (8.5 percent) and other positions.

The Future of Long-Term Care Staffing

Staff shortages in long-term care will become even more significant in the future. The number of Americans needing long-term care is projected to increase from 13 million to 27 million between 2000 and 2050, with the number of elderly individuals needing such care increasing from 8 million to 19 million (USDHHS 2003). Consequently, the USBLS projects that an additional 1.9 million direct care workers will be needed in long-term care settings between 2000 and 2010 alone (USDHHS 2003). As need for long-term care services increases over the coming decades, the supply of workers is not expected to keep up. The Health Resources and Services Administration (HRSA) (2002), for example, has projected that the current RN deficit is likely to increase from six percent to 29 percent between 2000 and 2020. Whereas medical advances and the graying of the population will result in a marked increase in the demand for nursing services, the number of nurses leaving the profession due to attrition and retirement will exceed the number entering the field. This growing gap in “caring capacity” will be apparent at all levels of staffing in every long-term care organization; the nation is training fewer and fewer geriatric specialists, including doctors, nurses, CNAs, home health aides, and advance practice nurses.

Thirty percent of the nation’s 670 baccalaureate nursing programs satisfy criteria for exemplary geriatrics education. However, fewer than 23 percent require a stand-alone geriatrics course. Only three of the nation’s 145 medical schools have geriatric departments, and fewer than 10 percent require a course in geriatrics. Given the limited capacity to produce geriatric specialists, it should not be surprising that only 21,500 of the nation’s 2.2 million practicing RNs are certified in geriatrics and only 6,600 of the nation’s 650,000 physicians are certified in this area—even though projections suggest that 36,000 geriatricians will be needed by 2030 (Kovner, Mezey and Harrington 2002; Reuben, et al. 1993).

Although 91 percent of nursing home residents have a significant mental disorder, only 1.7 percent of general psychiatrists provide services in nursing homes, with only 2,600 having received subspecialty certification in geriatric psychiatry since 1991. Training

in geriatric mental health is similarly lacking among psychologists and social workers (American Geriatrics Society and American Association of Geriatric Psychiatry 2003). Most direct care staff have little or no geriatric-specific training as well.

Challenges Recruiting and Retaining Staff

There are several reasons that many find long-term care unattractive, or choose not to stay after entering the field. One reason is the “second rate” status associated with working in this area, whether as a physician or an hourly employee making minimum wage. This stems, in part, from the widespread public perception that caring for the elderly is unpleasant and unappealing, along with media portrayals of some long-term care providers as profiteers more interested in making money than ensuring high-quality patient care. Based on a recent Kaiser Family Foundation (2005) national survey, nursing homes (35 percent) rank below pharmaceutical manufacturers (43 percent) and just above health insurers (34 percent) and managed care plans (30 percent) in the percentage of adults who believe that they are doing a “good job” meeting the country’s needs. This is in contrast to nurses (94 percent), doctors (69 percent), and hospitals (64 percent). Although most (69 percent) agree that nursing homes provide frail and disabled people a safe environment they could not have at home, twice as many believe that nursing homes make people worse off rather than better off (Figure 12). Further, most (74 percent) believe that nursing homes do not have enough staff; that their staff is poorly trained (60 percent); and that there is too much waste, fraud, and abuse by managers (58 percent).

Most direct care in nursing homes is provided by nurse aides. Despite public perceptions, providing direct care is physically and emotionally demanding, with injury rates exceeding those for almost any other profession. In 2003, workplace injuries in nursing homes and residential care facilities averaged 10.1 per 100 full-time workers, compared to 6.8 per 100 construction workers and 5.0 per 100 workers in all private workplaces (Wright 2005). There is also a high number of assaults on direct care staff, with 59 percent of nursing assistants in one study reporting that they were assaulted by residents at least once a week and 16 percent daily (Gates et al. 2002). Ensuring safety is also a concern among home care workers, who may, in fact, be at greater risk as they venture out into the community (Sylvester and Reisener 2002).

Heavy caseloads have been cited as one of the major reasons that CNAs and home care workers leave long-term care and that retention is higher in organizations

Views of Nursing Home Management

Strongly agree
 Somewhat agree
 Somewhat disagree
 Strongly disagree

They have staff who are concerned about the well-being of their patients



Managers of nursing homes are not concerned about the well being of their patients



Nursing homes don't have enough staff



The families of those who use nursing homes are not involved enough in what's going on



The staff at nursing homes are often poorly trained



There is too much waste, fraud, and abuse by managers of nursing homes



FIGURE 12

Source: Kaiser Family Foundation Health Poll Report Survey (conducted June 2-5, 2005)

with more staff (CMS 2002; Mickus, Luz and Hogan 2004; Trinkoff et al. 2005). Other frequently cited factors include inadequate initial training and continuing education, rotating assignments and limited involvement in decision-making, perceived lack of supervisors' value and respect, and little or no opportunities for professional growth and career advancement (Eaton 2002; Mickus, Luz and Hogan 2004).

Low wages are especially problematic. The long-term care workforce is among the lowest-paid in the nation. This is especially true of paraprofessional direct care workers, who, with a median hourly wage of \$9.20 in 2003, earned nearly 33 percent less than all U.S. workers (American Health Care Association 2004). Furthermore, only 48.3 percent of nursing home aides engage in year-round, full-time employment. Even fewer home care aides—34.3 percent—do so (Montgomery et al. 2005). In part because many

work only part-time, the median annual incomes for nursing home and home care aides in 2002 (\$13,287 and \$12,265, respectively) were barely above the federal poverty line of \$11,060 for a family of two, and well below that of \$16,700 for a family of four (Paraprofessional Healthcare Institute 2003a).

Direct care workers are also less likely to receive benefits, including health insurance, vacation time, tuition assistance, pension coverage, and child care (Fishman et al. 2004). This is especially true in home care, where agencies often “fill their rosters with as many part-time aides as they can hire, train them to minimum required standards, and assign work with little regard for the aides’ need for full-time hours or other professional treatment. As a result, turnover in the industry is high, care provided is erratic, and both home care aides and home care clients suffer” (University of Wisconsin Center for Cooperatives 2005, p. 1).

Recruitment and retention represent significant costs, both for long-term care providers and for the quality of care that they provide. Direct costs include the expenses of separation (exit interviews and other processing), vacancy (overtime pay, temporary staffing, and worker injuries), and replacement (Seavey 2004). These costs range from \$2,500 for aides to \$7,000 for RNs (Castle and Engberg 2005; National Commission on Nursing Workforce for Long-Term Care (NCNWLTC) 2005). In addition, there are indirect costs associated with lost productivity (less effective temporary workers and overextended employees), lost client revenues (less capacity with which to attract new residents or care for existing residents), deterioration in organization culture and employee morale, and reductions in service quality (Seavey 2004). These direct and indirect costs imply that successful efforts to reduce turnover will create a significant return on investment, and several strategies have been adopted to improve workforce recruitment and retention in long-term care. The most prominent have been attempts to change the workplace environment, to increase wages and benefits, and to create opportunities for career advancement and training. Work-oriented redesign was examined in the context of the culture change movement in Chapter IV. Wages and benefits and career advancement and training will be examined here.

“The quality of the experience and the health of the frail elderly will be directly related to the quality of people recruited, the level of training, and the level of retention. Achieving a quality experience will almost certainly require greater resources than we currently allocate to those goals. ... As a country, we have to confront that. ... If you don’t want to pay for higher quality and organize for higher quality and train for higher quality, then expect the bad experiences or the inadequate experiences. There will be a consequence of that decision. But don’t kid yourself.”

—Former Speaker of the House Newt Gingrich, Co-Chair

Wages and Benefits

With lower wages and fewer benefits and advancement opportunities than in other industries, long-term care providers have difficulty competing with employers offering less physically and emotionally demanding low-pay jobs (Paraprofessional Healthcare Institute 2003a). One study found that inactive nurse aide registrants in North Carolina who left long-term care earned more income, experienced less unemployment, and cycled through fewer positions each year than registrants still employed in long-term care (Kondrad, Morgan and Haviland 2003). Long-term care providers have a difficult time competing with hospitals, where wages and benefits for RNs and paraprofessionals workers are considerably higher (USDHHS 2003). For example, the average annual salary for RNs and nurse aides are 17 percent and 9.4 percent lower, respectively, in nursing homes than hospitals. Additionally, nurse aides are nearly twice as likely to receive health insurance and pension coverage in hospitals as in nursing homes. In 2001, \$2.7 billion would have been needed to increase wages and benefits to achieve parity in compensation between hospital and nursing home staff (Decker, Dollard and Kraditor 2001); this figure would be considerably higher if it accounted for the lower wages and fewer benefits in home care. The competition for staff is likely to increase as the demand for workers trained in geriatrics rises in acute care hospitals along with nursing homes and home care providers.

As of 2003, 26 states had sought to increase compensation through wage pass-through policies in which a reimbursement increase from a public source—usually Medicaid—is directed toward increased wages and benefits for direct care workers (Harmuth and Dyson 2004). Nine states extended the pass-through to nursing home workers only, four to home care workers only, and eight to both nursing home and home care workers (Paraprofessional Healthcare Institute 2003a).

There has been little systematic evaluation of wage pass-through programs. Of 12 wage pass-through states responding to a 1999 survey, four reported that they had a positive impact on recruitment and retention, three reported that they had no impact, and three said the impact was unknown (North Carolina Division of

Facility Services 2000). Results from four unsophisticated evaluations have been mixed: Michigan experienced a 61 percent increase in CNA wages and a 21 percent decline in turnover over the 13 years of its wage pass-through program; wages for nurse aides in Massachusetts increased by 8.7 percent during the first year of that program and vacancy rates stabilized; turnover in Kansas nursing home declined from 111 to 101 percent after one year of implementation; and total compensation for direct care workers in Wyoming increased from \$9.08 to \$13.74 per hour and turnover declined from 52 to 37 percent over the first three months of that state's wage pass-through effort (Harris-Kojetin, et al. 2004; Paraprofessional Healthcare Institute 2003a).

Though the efficacy of wage pass-through programs has yet to be fully examined, most agree that low wages contribute to high turnover, especially among direct care workers. Further, because wage pass-through programs provide a mechanism to attract and retain a higher quality workforce, they have garnered support from both industry and resident advocates. Given the widespread support for such programs, there is a greater need to rigorously evaluate the staff and wage pass-through policies that are in place. There is also a need for more effective auditing and enforcement procedures to ensure that additional funding is spent on its intended targets. Provider accountability is critical, though it can be potentially burdensome for states.

Training and Career Advancement

The federal government requires that CNAs and home health aides work under the supervision of an RN and receive at least 75 hours of training—16 hours of clinical training and 59 hours in the classroom learning basic care-giving skills. Within four months of employment, these workers must pass a state-sanctioned competency test to work for a Medicare- and/or Medicaid-certified nursing home or certified home health agency, and they must receive an additional 12 hours of training annually to maintain certification (Paraprofessional Healthcare Institute 2005). By contrast, home care aides or personal care workers hired by state, local, or nonprofit agencies and independent providers hired directly by consumers may or may not be subject to training requirements and may or may not work under the supervision of an RN (Stone 2004).

Because of rising acuity and frailty, especially in nursing homes, there is growing concern that current training requirements do not adequately prepare direct care workers (Salsberg 2003). This has spurred 26 states to extend mandatory CNA training beyond the federal standards, including 15 states that require 100 or more hours (Office of the Inspector General 2002). CNAs working in Missouri must receive at least 175 hours of training. Virginia recently expanded its minimum number of training hours from 80 to 120. Ohio, New Mexico, and Florida have developed new rules standardizing training for CNAs and/or other direct care workers throughout their states (Harmuth and Dyson 2005; Office of the Inspector General 2002).

A number of states have also extended training requirements for home health aides. Wyoming requires 91 hours of training, Washington 105. Several states require home health aides to be certified as CNAs with, perhaps, additional training on topics related specifically to home care. Although Maryland has no training requirements for personal care aides, home health aides must receive CNA certification in addition to 12 hours of in-service training. Many states require training for personal assistance workers. Maine requires 40 hours of training for all personal care assistants. Some states require personal care assistants to complete the same training as home health aides; others require only a few hours of in-service

training (Harmuth and Dyson 2005; Paraprofessional Healthcare Institute 2005). There is also growing awareness of the need to support self-directed consumers who hire and train their own workers (Paraprofessional Healthcare 2004).

Recently, there has been interest in providing new workers with more intensive and structured orientation, with some state and provider initiatives adopting peer mentoring systems for new employees (Paraprofessional Healthcare Institute 2003b). New York's "Growing Strong Roots" peer mentoring program, for example, pairs new employees with exemplary and experienced CNAs who acquaint them with the customs, resources, and values of their facilities. Both mentors and mentees receive additional training. Mentors also receive formal recognition and a salary increase or bonus. In six nursing homes participating in the program's initial evaluation, retention among new CNAs and their mentors increased by an average of 17 and 21 percent, respectively. No significant increases were identified in comparison homes. The program has since added an additional 22 facilities to its roster (Harris-Kojetin et al. 2004).

Another initiative that promotes a more nurturing approach is the Learn, Empower, Achieve, and Produce (LEAP) program developed by Mather Lifeways, a long-term care provider in Illinois. Nurse managers, RNs, and LPNs participate in a six-week workshop to develop leadership, role model, clinical gerontological, and team building skills. CNAs participate in a 14 hour, seven week workshop that focuses on career and skill development in a variety of areas, including person-centered care, communication, care team building, and mentoring. CNAs that complete this training become Level 2 CNAs and receive salary increases ranging from \$0.50 to \$1 per hour. LEAP was piloted in 1999 and replicated at three other sites between 2000 and 2002. Both nurse and CNA turnover declined among participating facilities. Both nurses' and CNAs' perceptions regarding their work empowerment, job satisfaction, and organization's communication improved significantly; these improvements were associated with fewer health deficiencies cited on state inspections. More than 400 "specialists" from 26 states have been trained to replicate LEAP in their own facilities (Hollinger-Smith 2002; National Clearinghouse on the Direct Care Workforce 2005).

Growing Strong Roots, LEAP, and Cooperative Home Care Associations (see Chapter IV) incorporate career ladders, which allow workers to acquire skills to grow professionally and advance through a progression of better-paying jobs. There are two basic types of career ladders: those that provide workers with opportunities for higher pay and greater professionalization within the context of their current positions, and those that provide staff with financial incentives to participate in supplemental “job-enhancement” training programs. The latter include programs that create formal tiers within the same occupation and programs that enable workers to move progressively from one occupation to another—for example, from CNAs or home health aides to LPNs or RNs.

Effective career ladder programs integrate training with the work and personal lives of employees by offering courses at convenient times and providing access to financial assistance for tuition, books, and other expenses. Several successful programs have formed partnerships with local workforce investment agencies, community-based organizations, unions, community colleges, and other educational institutions to design and implement appropriate training programs and career advancement opportunities (Fishman et al. 2004). In fact, community colleges throughout the country report collaborative efforts with health care providers to address nursing shortages in their areas (NCNWLTC 2005). Joining forces with a local community college, for example, five Genesis ElderCare facilities located on the same campus in rural Massachusetts provide entry-level employees with formal career ladder classes and college courses, including an on-site evening LPN program. This program has been funded, in part, by the State of Massachusetts Extended Care Career Ladder Initiative, which supports several organizations’ efforts to develop opportunities for direct care workers to increase their skills, reducing turnover and vacancies in long-term care. Although initially targeted at CNAs, Massachusetts Extended Care program has since been expanded to home care (NCNWLTC 2005). On a larger scale, the provider-educational institution approach has been used by both private foundations and public agencies as they seek to encourage more health workers to enter geriatrics.

Online training and other online resources are playing an increasing role in integrating health profes-

“Professional schools have experienced difficulties recruiting students who will train to be a geriatrician, a geriatric nurse, a geriatric psychiatrist, or a geriatric social worker ... I have been involved in aging for 30 years now and it’s very clear that unless there is financial assistance for students who may be studying for a professional degree you do not attract people to aging. It’s unfortunate, but ageism is alive and well, and most students are still inclined to select work with children and families as opposed to the elderly.”

—Jeanette Takamura, Ph.D., Commissioner

sional training into work and personal lives, encouraging low-income individuals who have families and other full-time obligations to pursue more advanced careers in long-term care. Indeed, without online resources, many facilities might not be able to comply with regulatory requirements for continuing education. Websites like MyZiva.com provide nursing homes with a comprehensive array of management tools and resources, including 100 continuously updated online courses and educational materials. Online training now constitutes 10 percent of all higher education, including bachelor’s, master’s, and doctorate programs in health administration and nursing and certification programs for medical and nurse assistants (eLearners 2005; OnlineCareers.com 2005). It has been suggested that funding for expanded online programs be provided

through state and federal grants (NCNWLTC 2005; Salsberg 2003). States such as North Carolina and Minnesota have already designated funding to support on-site online training for CNAs in nursing homes.

Financial incentives may prove an especially attractive means of spurring people to pursue educational opportunities in long-term care. This is true not only for CNAs, home health aides, and LPNs looking to advance their careers, but also for physicians, nurses, and others who might not otherwise choose careers in this area. There has been growing interest among state and federal officials in directing scholarships and loan forgiveness programs toward both the professional and paraprofessional segments of the long-term care workforce. Although both approaches may be effective in encouraging financially better-off individuals to pursue careers in targeted specialties, scholarships may be more effective than loan forgiveness in stimulating financially disadvantaged students who may not have the up-front money for tuition. This is especially true when tuition is high, education takes several years, and loan repayment is competitive or uncertain. Loan forgiveness, however, may be more easily connected to service obligation in a particular geographic area, facility, or field (Salsberg 2003). For example, medical students sometimes receive scholarships, fulfill their obligation, and immediately move on. Loan forgiveness programs, which do not require individuals to sign up for service years in advance, but instead after their education has been completed, allow individuals to choose the areas within which to work, thereby increasing the likelihood that they will stay for longer periods of time.

Several state and federal programs provide loan forgiveness and tuition assistance. HSRA provided \$15 million in loan repayment, for example, under its Nursing Education Loan Repayment Programs to nurses who agreed to serve at least two years in designated facilities (USDHHS 2003). At the state level, the Michigan Nursing Scholarship program offered \$4 million in scholarships to RN and LPN students in exchange for a commitment to work in a Michigan health care facility after graduation (NCNWLTC 2005). Whereas Minnesota established a program to fund scholarships to non-administrative workers looking to advance their careers in long-term care, Virginia implemented a scholarship and loan repayment program for

students who agree to work in the area for a specified period of time. New York's Workforce Retraining Initiative not only provides support to workers in meeting the requirements of existing positions, but it also assists eligible workers as they transition to new jobs within health care (Harmuth and Dyson 2005). Several government programs also provide low-income or unemployed individuals the opportunity to pursue employment in the health field, including nursing homes. The federal Work Investment Act (WIA) has funds that can be used to give low-income or unemployed individuals paid work experience and on-the-job training to help them become more employable, and the Welfare-to-Work program helps welfare recipients and low-income non-custodial parents in high-poverty areas obtain jobs in the public or private sector (Salsberg 2003; Stone and Wiener 2001).

Solving the Workforce Crisis

Federal and state programs and other efforts aim to stimulate the supply of nurses and other health care workers. However, shortages are more acute and the work generally considered less desirable in the long-term care sector. Consequently, there is widespread agreement that key stakeholders could do much more to develop programs to recruit individuals at all levels into long-term care—including loan forgiveness, scholarships, wage enhancement, training, and career ladders. The long-term care workforce, including CNAs, home health aides, personal care assistants, LPNs, RNs, advanced practice nurses, administrators, and geriatricians, must be expanded, supported, and trained for the multiplicity of tasks and responsibilities necessary to deliver high-quality care to frail and chronically disabled individuals in both residential and home- and community-based settings. This is true in the context of both current workforce deficits and the even greater deficits to come if administrators and workers do not engage public policymakers in solving the workforce crisis in long-term care.

CURRENT REGULATORY PRACTICES in the long-term care field are based on inspections of patients' records, some observations of patients and care practices, and a review of policies and procedures. While recognizing the importance of holding providers accountable to minimum standards, providers have expressed widespread frustration with the way states administer the federal survey process. Further, there is a strict divide between regulators' role to inspect and sanction providers and the provision of any advice, education, or consultation to providers. The latter are designed to improve quality, the former to assure quality. The provider's appetite for quality improvement will be limited so long as the principal critic that must be satisfied is the inspector.

Many bemoan the stifling consequences of excessive regulation, but Mark Schlesinger, a noted public policy analyst, has said that "the regulation of nursing homes remains highly legitimate for the public and an ongoing concern even in the most conservative of states. This is in many ways a remarkable testament to the perceived need for regulation as a safeguard for the average citizen. These protections could be more effective, and they could be implemented more equitably. But they clearly have a deep-rooted and lasting place in the contemporary American health care system" (Schlesinger 2004; p.9).

"The Center for Medicare and Medicaid Services has tried to help surveyors that inspect nursing homes recognize appropriate care by providing guidelines and investigative protocols. But these are not systematic ... and do not clarify which external standards of care are relevant.... The result is: surveyors use their judgment, which may simply reflect personal opinions based on habits, hunches, and limited understanding. This is reflected in large inter- and intra-state differences in survey results, frustrating facility administrators."

—Steven Levenson, M.D., 2001

Government Regulation of Nursing Homes

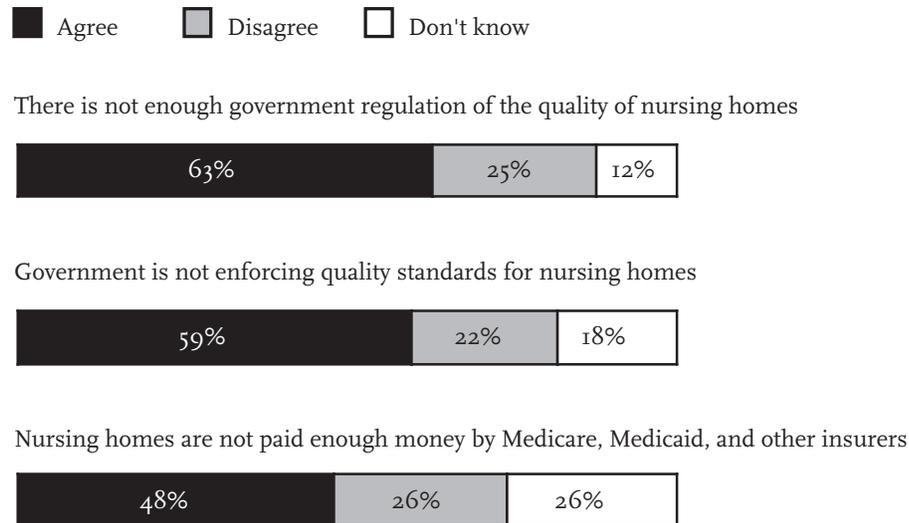


FIGURE 13

Source: Kaiser Family Foundation Health Poll Report Survey (conducted June 2-5, 2005)

Indeed, according to a recent Kaiser Family Foundation (2005) poll, more than 60 percent of the public does not feel there is enough government regulation of nursing homes. Nearly as many people feel that the government does not enforce quality standards in current regulations. Figure 13 clearly suggests the American public's appetite for regulatory action vis-à-vis long term care, as well as the limited trust in the protection provided by existing government regulations. The relationships among regulators, providers, clinicians, quality improvement organizations and, of course, the consumer, needs to be re-examined in order to realign incentives, to be "smarter" about regulations, and to regulate more transparently.

Long-Term Care Regulation Today

All long-term care providers are governed by state regulations. Typically, states' health departments are the principal regulatory entity authorized by state legislatures to devise, and monitor provider compliance with, state regulations. Although all state health departments license nursing homes and home health/home care agencies, not all health department license assisted living facilities, day care centers, or even private duty nursing and case management services. These latter services may, in some cases, be licensed by a state agency on aging or by a social service department—or not at all.

Some states make information on licensed providers more accessible to the public than others. At a minimum, lists of licensed providers should be available, but in some states not even this information can be accessed electronically—and, even when this information is available, it is often not up-to-date. Very few states make accessible comprehensive listings of serv-

ice providers across service type to allow officials to assess the adequacy of service capacity or to allow potential users to choose among alternative services. In addition to state licensure requirements, nursing homes and home health agencies must also comply with federal Medicare regulations if they serve patients on Medicare. These regulations govern many aspects of the services offered to frail and elderly clients, as well as the manner in which services or treatments are rendered. Nursing homes participating in Medicare or Medicaid (over 90% of all licensed facilities) must comply with the most extensive set of regulations; they are subject to elaborate annual surveys by state inspectors. Indeed, in the case of nursing homes, the federal conditions of participation in the Medicare/Medicaid programs effectively substitute for state licensure, and CMS actually contracts with state inspectors to conduct the relevant surveys, following a federally designed inspection protocol. Further, nursing homes, in addition to Medicare-financed home health agencies, are mandated to implement an extensive patient assessment information system that documents the clinical care plan—from which information about payment and quality of care is derived.

Although assisted living facilities have proliferated over the past decade and many of the people served in these institutions require levels of assistance comparable to those provided in nursing homes, the federal government exercises minimal oversight. In the case of assisted living, states establish and enforce licensing standards rather than the federal government, even though at least six states have Medicaid waiver programs allowing nursing home-eligible individuals to reside in assisted living and more than half of all states have demonstration programs allowing payment for assisted living under those programs' authorizing waivers (U.S. General Accountability Office 2004). In 1998, it was estimated that about 40,000 nursing home eligible Medicaid recipients resided in assisted living (Spillman, Liu, and McGilliard 2002).

In addition to assisted living, adult day care has also proliferated nationally in the past decade. Of 3,500 programs in 2001, 21 percent operated on a medical model, 37 percent on a social model, and the remainder on a combined medical-social approach (Robert Wood Johnson Foundation and Wake Forest University School of Medicine 2002). In general, adult day programs

provide a wide array of services, many of which are reimbursable—and therefore subject to federal conditions of participation—if day care is an allowable service under a particular state's Medicaid plan. In some states, programs with a medical component may be regulated by health departments; in others, the social or aging services offices regulate the programs.

The regulatory role of states' departments of elderly affairs (or the like) relative to Medicaid-covered services is often organized like that of a purchaser—requiring providers to meet certain standards. This is in sharp contrast with licensure authority, which is generally retained by the health department. Licenses are required before the provider can serve anyone, whereas a purchaser's clout applies only to a particular group, generally those with Medicaid insurance. The legal differences between these two forms of regulatory authority are substantial. It is not necessarily clear which approach is more effective in assuring the quality of services provided to long-term care recipients; the nature of the laws, precedence in administrative rulings, and the nature of stipulated appeals processes are all factors in determining the more effective approach. A major condition of participation in a Medicaid (like Medicare) reimbursement program is typically that the provider be licensed; in some states, however, certain types of providers, such as adult day care centers or case management companies, are not yet licensed, making the licensing approach a non-starter and the condition of participation approach necessary by default.

Cops vs. Consultants

An ongoing debate in regulatory circles is whether regulators should only review performance and apply sanctions, or whether they should also consult, sharing information with providers about how others in the same field have been able to solve problems that lead to violations. In health care, Medicare and Medicaid have chosen to accept (“deem”) the accreditation of hospitals undertaken by the Joint Commission on the Accreditation of Health Care Organizations (JCAHO). The review and accreditation visits for hospitals are seen as costly, and they require that hospital undertake a significant amount of preparation. Nonetheless, the hospital visit process and resulting summary is considered more helpful than the annual nursing home inspection. Discussions about having JCAHO “deemed” as a substitute inspector for nursing homes, however, have not been well-received. Several studies comparing the results of nursing home inspections undertaken by JCAHO and those undertaken by state health officials found substantial differences, leading some to conclude that JCAHO may be too lenient.

The introduction of the Quality Improvement Organizations (QIOs) is a recent development. Intended to stimulate health care providers to undertake continuous quality improvement interventions, CMS has made a major investment in QIO efforts in long-term care (Baier, Kissam, and Gifford 2005). QIOs can be viewed as government’s effort to provide consultative information and support for providers in order to help them improve and solve their quality problems; state inspections, by contrast, are an essentially independent evaluative function, offering no solutions, that merely determine whether providers’ activities meet existing standards. In spite of major efforts over the past decade on initiatives to improve quality, many see fundamental contradictions between the current system of regulatory oversight and sanctioning and the ethos that underpins organizational efforts to undertake “continuous quality improvement.”

Whether this bifurcation of the oversight and quality improvement roles is appropriate is unclear. The introduction of QIOs has raised other issues, as well, including, “How much, if any, communication should there be between the QIO and the regulatory agency? Should state inspectors be informed of the progress

“The fundamental issue is: are the regulators cops or are they consultants? Right now it’s just a contentious thing. Does the denial approach to regulation currently in use criminalize a lot of stuff that might otherwise be more productively resolved?”

—Monsignor Charles Fahey, Commissioner

providers have made in the quality improvement arena—or whether providers are participating in such efforts at all?” It is not clear that the quality improvement goals CMS asks the QIOs to address are necessarily relevant to the most severe or prevalent problems identified in inspections. Clearly, it would be ideal to establish an iterative process in which inspectors identify performance problems and QIOs then help providers design quality improvement interventions to ameliorate the problems that have been identified.

Regulatory Inconsistencies

The current process of inspection of nursing homes, assisted living facilities, home health agencies, day care centers, and hospices is undertaken in accordance with an extensive set of instructions written into state law and government regulations and/or stipulated by the primary purchasers of care. Many aspects of the inspection process are specified in considerable detail, including the selection of patients' charts to review, investigative protocols, and guidelines for determining the appropriateness of care. However, though quite detailed, the process is insufficient to determine whether suitable interventions were made in the case of a particular patient's care. Further, guidelines use language that is subject to interpretation; the result is that inspectors use their own judgment, which may or may not be consistent with that of others on their team or that of teams in different regions. This is one reason that we find such large inter-state variation in survey inspection results. Indeed, one of the most disconcerting aspects of government regulation of long-term care is its inconsistent application both within and across regions over time. Providers want consistency in the regulatory environment—it is difficult to play by the rules if the interpretation of the rules keeps changing or varies from one area to another.

We examined inter- and intra-state variation in the number and severity of inspection citations for deficiencies in regulatory performance. The inspections of nursing homes, for which data are readily available, are an exemplar of a pervasive phenomenon believed to extend to the inspections of assisted living facilities and other state licensed providers. Figure 14, in particular, reveals substantial inter-state variation in the average severity-weighted number of deficiency citations levied against nursing homes in 2004. The severity-weighting scheme was devised by CMS and assigns many more “points” to deficiencies that represent a clear and present danger to residents and those that contributed to actual harm to one or more residents.

These data actually combine two very different phenomena: the probability that a facility is cited for a severe deficiency, and the average number of deficiencies facilities are cited for. These are not necessarily correlated. For example, the average facility in California was cited for about 13 violations in 2004, but

“So you're the consulting police, if you will. 'First, we try to fix it. Then, if we have to, we put you out of business.' It's a sequencing thing, it's not an either/or kind of thing. We're right at the edge of breakthroughs in models that will be dramatically more effective in raising quality than anything we've seen in the last 50 years. It behooves us to develop an inspection process that promotes the further diffusion of these models.

—Former Speaker Newt Gingrich,
Commission Co-Chair

only about five percent of facilities in the state were cited for causing actual harm or immediate jeopardy. On the other hand, New Hampshire averaged only a bit more than five deficiencies per facility, but more than 15 percent of facilities were cited for causing actual harm or placing patients in immediate jeopardy. While there may be some difference in the absolute underlying level of quality of facilities in these two states, it is unlikely that this difference is sufficient to fully explain the different patterns of deficiency citations.

The stringency of regulatory action also changes over time in response to political pressures and local scandals. In a recent case in New York, for example, the Attorney General placed hidden cameras in a patient's room and observed the lack of responsiveness of facility staff (Office of New York State Attorney General Eliot Spitzer 2006). From a national perspective, there are clear trends in the propensity of inspectors to cite facilities for deficiencies. Some states appear to have a

State Average Score of Scope-Severity Weighted Deficiencies Per Facility, 2004

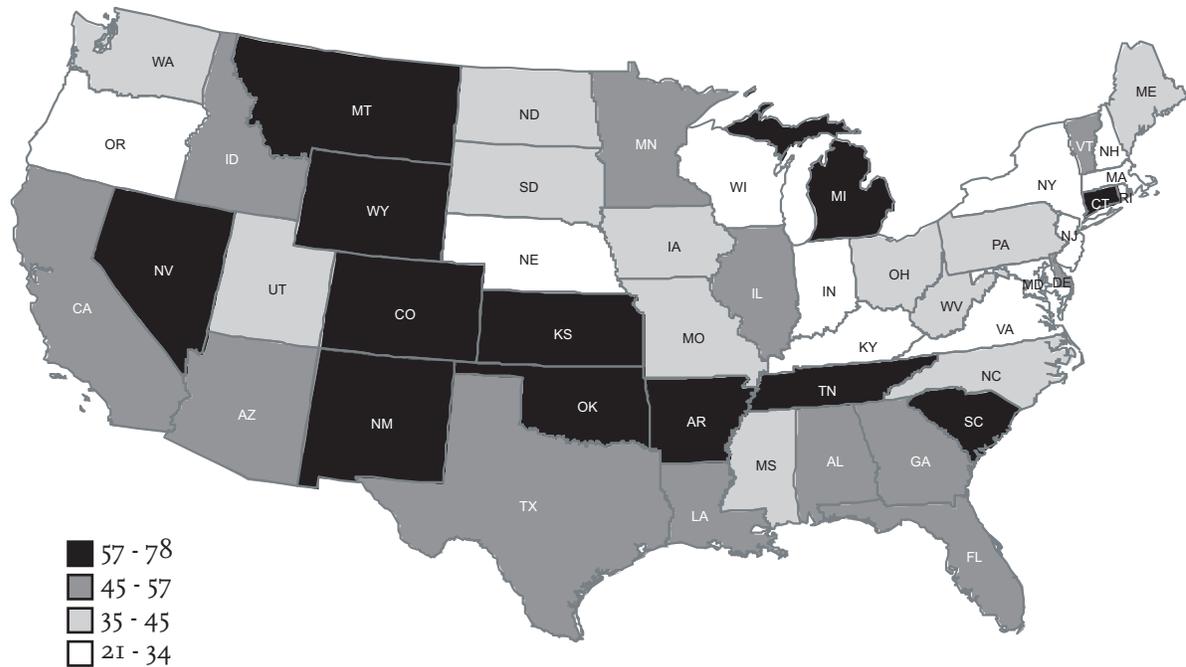


FIGURE 14

Source: Online Survey, Certification, and Reporting (OSCAR), 2004

much higher threshold for citing violations than others (California has a high average number of violations, while most Northeastern states have a low average); over the past decade, however, all states seem to have fluctuated in their propensity to cite facilities. Figure 15 below represents the change, between 1995 and 2004, in the likelihood that a facility in a given state would be cited for contributing to the actual harm or immediate jeopardy of a resident. The line in the middle of the box for each year represents the median state, and the lines at the top and bottom of the boxes represent the top and bottom states. During the late 1990s, all states were more likely to cite their facilities for these kinds of problems, due in part, perhaps, to the increased emphasis placed on regulatory enforcement under the Clinton Administration (Centers for Medicare and Medicaid Services 2000). In the most recent years, both the likelihood of such a citation and the variation between states in the number and likelihood of serious deficiency citations have fallen. Whether this change

Trends and Inter-State Variations in the Percentage of Facilities Cited for Actual Harm or Immediate Jeopardy to Residents, 1995-2004

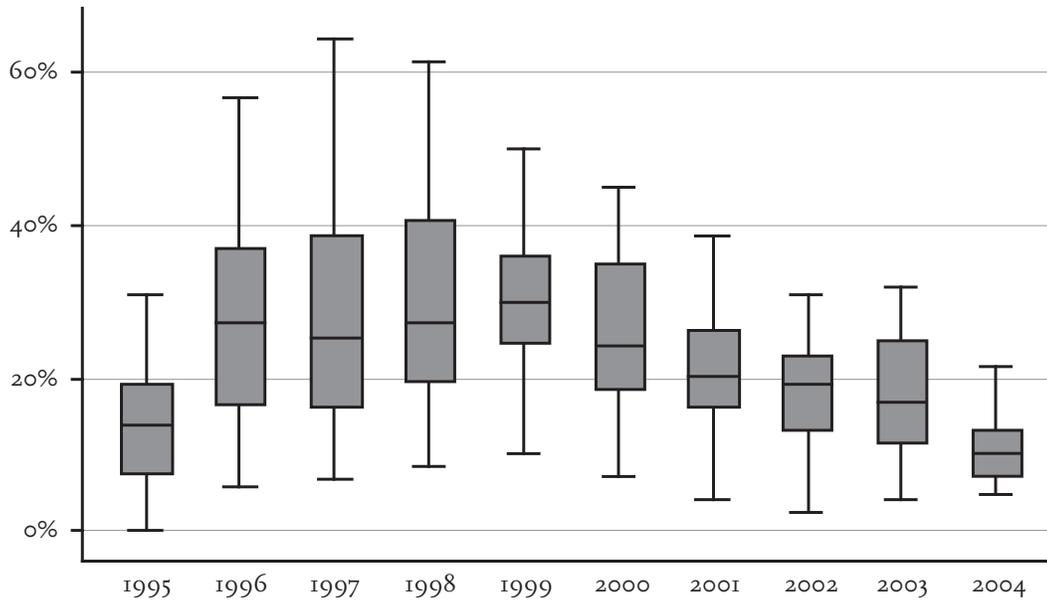


FIGURE 15

Source: *Online Survey, Certification, and Reporting (OSCAR)*, 2004

reflects “real” improvement in quality, or merely a shift in the intensity of regulatory oversight, is unknown.

In large states, multiple inspection teams are involved in inspecting facilities, based on proximity to regional offices. Examinations of California, Florida, New York, Illinois, Michigan, and other states all reveal considerable intra-state variation in both the number and likelihood of serious deficiency citations (Figure 16). In the Florida Panhandle, for example, facilities have far fewer severity-weighted deficiency citations than do facilities near Naples. Similarly, facilities in northern California are much more likely to be cited for virtually any given deficiency than are facilities in Orange County in southern California. While some of this variation may be related to real regional variation in provider quality, attributable to regional differences in wealth, there is far more variation than can be explained by this factor alone. In addition to variation-among citations rates, a recent comprehensive study of state regulation and enforcement during 1999 revealed

Florida County Average Deficiency Score per Nursing Home in 2004 (Weighted by Scope-Severity)

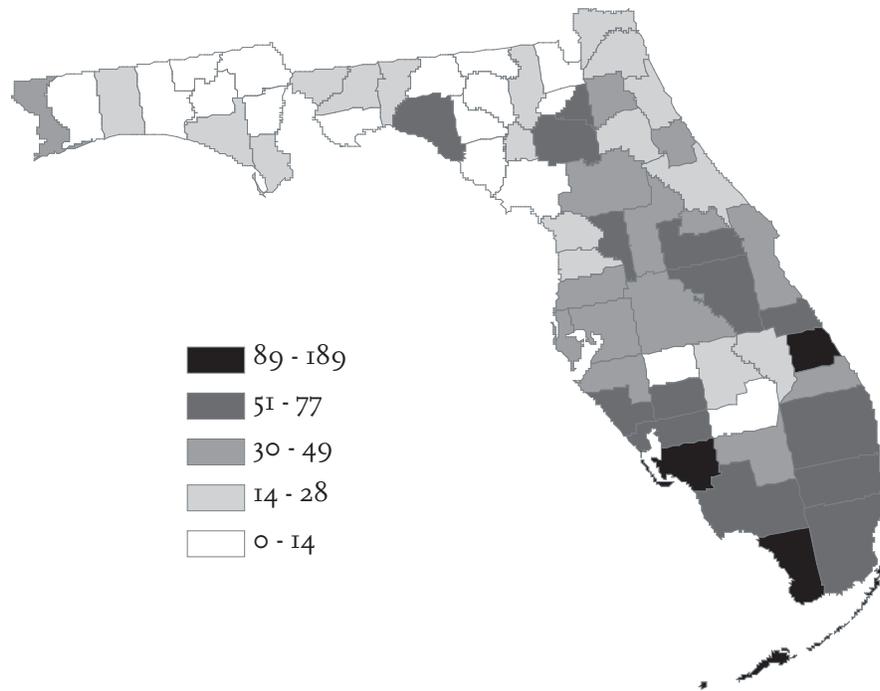


FIGURE I6

Source: Online Survey, Certification, and Reporting (OSCAR), 2004

highly variable rates of censures issued by state and federal officials. For example, 61 percent of civil monetary penalties were issued in only 16 states; eight states issued none. Interestingly, most state regulators have not found monetary penalties to be effective in achieving responsiveness by facilities. Denial of payment for new admissions, another “intermediate sanction” available to regulators, was instituted by only 32 states; several states statutorily prohibit this approach (Harrington, Mullan and Carrillo 2004). Finally, decertification or withdrawal of state licensure is applied in exceedingly rare circumstances, although much more frequently for nursing homes located in poor communities and for those serving predominantly Medicaid patients. In sum, there is substantial inter-state variation in the application of sanctions for apparent infractions of nursing home regulations, but there is still no real evidence that states that take more stringent enforcement action have better-quality nursing homes.

Regulating Smarter

The effectiveness of the survey process is highly dependent on the skill of the surveyors and the particular tasks they have been asked to undertake. It is much easier to train a surveyor to examine the Medication Administration Record for charting inconsistencies or to look for records of in-service education or minutes of committee meetings than it is to disentangle the consequences of inappropriate or insufficient treatment in a patient's chart. Process criteria are much easier to implement and review than documentation of the prevalence of facility-induced poor care.

Few states, if any, arm inspectors with computerized clinical information about all facilities' residents, or even just those residents "at risk" of experiencing untoward morbidity without appropriate care. Indeed, inspectors often have to rely on their memory and substantial paper files to assess how things have changed since the last inspection. While computerized decision-support tools, predicated upon historical survey performance, could provide guidance in conducting inspections and greatly enhance consistency and comprehensiveness, these tools have not yet been developed. Instead, states have multiple, disconnected nursing home quality compliance reporting systems, including state inspections, a complaint system, and a mechanism for the federally-supported "ombudsman" program to report on quality problems. Few states have complete reporting systems in place for complaints, fewer still for the ombudsman program or for the final disposition of civil penalties for violators of selected regulations. Such systems are a critical component of a quality monitoring system, and it would be helpful if all were complete and integrated, such that inspectors would know whether and how each complaint is or is not related to quality problems identified on the last inspection.

Such a "smart" regulatory oversight system would provide meaningful, up-to-date information on nursing home performance. It would be far more useful than the current system, in which states are drowning in paper work, receive inconsistent messages from CMS regional offices, and, therefore, exhibit inconsistency in the application of sanctions and citations of homes for quality problems.

Information and the Regulatory Process

Over the past decade or more, CMS has introduced mandatory clinical assessment and patient status reporting tools in nursing homes and Medicare-certified home health agencies. This information, which describes the clinical condition and clinical needs of the patient, has been used to create case mix-adjusted payment systems in both settings and to characterize the quality of the long-term care provider. Resulting measures of quality are based on the aggregation of information about the incidence and prevalence of conditions like pressure ulcers, deteriorating function, and hospitalization.

Since 2002, CMS's Nursing Home and Home Health Compare websites have been reporting information about the quality of long-term care provided in nursing homes and home health agencies. The range of measures of care quality has been limited to those obtained from the clinical information systems and, in the case of nursing homes, the results of annual inspections. Nineteen states also maintain nursing home report cards accessible through public websites (Castle and Low 2005). These too have been designed to provide clear and understandable information in order to increase consumers' awareness of quality differences among providers (Mukamel and Spector 2003). However, the amount, type, and format of information made available to the public vary considerably.

Although most people want to know about quality before they choose a health care provider, there remain relatively few easily digestible sources of information for consumers. Although long-term care is multi-dimensional, existing report cards offer primarily clinical information, rather than information about quality of life or patient satisfaction (Kane et al. 2004; Lowe et al. 2003)—not to mention staff turnover rates, worker satisfaction, or medication errors. To empower individuals and families to make reasonable, responsible, and informed decisions, policymakers need to ensure the relevance of long-term care report cards to the people using them. Policymakers also need to ensure that information is presented in a user-friendly way, organizing the data so that it allows users to say, "This is the kind of person I am," or "Here's the kind of long-term care I would like to have, now let's see if I can find a provider close to me that meets my requirements."

A prerequisite to "smarter" regulation is consistent, reliable, and valid data from providers as well as inspec-

tors. To use the Internet to search for a nursing home, for example, consumers and their advocates are forced to distinguish between regional variations that reflect real differences in provider quality and regional variations that are artifacts of inconsistent inspection practices. Further, families living in and near states with different regulatory systems might need to compare facilities in both states—though the information made available may be inconsistent or, at worst, non-comparable. Despite the importance of information quality, few have considered its role in helping consumers make decisions. Even the most recent study by the General Accountability Office on progress in nursing home oversight fails to make the connection between historical inconsistencies in the oversight process and the adequacy of the information base on which enforcement decisions are made and publicly reported quality data are generated (U.S. Government Accountability Office 2005b).

While, on average, there is substantial evidence that federally-mandated clinical assessment data are reliable and valid, there is also considerable evidence that the quality of the data varies from provider to provider and state to state (Mor, et al. 2003b; Roy and Mor 2005). If providers are to be compared and judged on the basis of this information, it is imperative that the data be truly comparable. Only then can we be assured of valid and meaningful results.

Inter-state comparisons have revealed that almost half of the observed inter-state differences in selected quality measures are due to systematic coding differences in the assessment items that make up the quality measures (Roy and Mor 2005; Wu, et al. 2005). Several small studies comparing nursing home providers' performance in areas such as pain management and incontinence care have also found substantial inter-facility and inter-state differences in the prevalence of clinical conditions seemingly unrelated to differences in the patients studied (Schnell et al. 2004; Schnelle, Osterweil and Simmons 2005).

CMS now reports quality performance measures for nursing facilities and home health agencies on a quarterly basis. Rules govern when such measures can be reported—based on the number of patients for which a measure can be calculated—but even when there are at least 20 or 30 patients, the result can be quite volatile (Mor et al. 2003a; Sangl et al. 2005). For

example, it is not uncommon for the measure of the proportion of patients declining in personal care functioning to change from well over 30 percent in one quarter to well under 20 percent in another, shifting the providers' quality rank from near the top to near the bottom (Mor 2005). Statistically, less than 25 percent of the variation in a quality measure reflecting June performance can be explained by the preceding measure from March. Further, throughout the country, the correlation between measures such as functional decline and pressure ulcer prevalence is less than .05, meaning that providers doing well in one measure may not be doing so well in another. If consumers, families, and advocates use this information to choose a provider, it is because they believe that the past will be a good predictor of the future. To the extent that the quality measures are volatile, they will not be good predictors of future performance—nor can they guarantee that good performance in one area means that there will be good performance in another.

Improving Data Quality

The lack of uniformity of regulatory inspections and the clinical assessment process calls out for improvements in the quality of the data used and the processes by which it is assembled. It is imperative that inspectors adhere to a precise protocol for sampling clinical charts, observing patients, and determining whether care meets basic requirements. Schnelle, Osterweil and Simmons (2005) propose that inspectors adopt research-based observational protocols to ensure that inspectors do the same thing in multiple settings, and that specific guidelines be adopted for what constitutes a care problem or deficiency in each relevant clinical domain.

Inter-state variability in clinical assessment data is natural, given that state provider organizations have periodically sponsored and instituted training programs for nursing home staff on how to conduct the required assessments; such statewide gatherings of clinical assessment personnel may reinforce errors made in common by staff in all a state's nursing homes. Further, providers or assessors who call the available "help line" to inquire about aspects of the required clinical assessment are connected to a state official in the health department rather than to a small cadre of a national CMS employees or contractors. National centralization of assessor training and assistance would likely ameliorate inter-state differences in interpretation of assessment items.

Improvement in the quality of clinical assessment data would also be possible through "real time," internal consistency checks for any given assessment, as well as between assessments of the same individual. Just as individuals unable to eat independently are unlikely to be able to walk 50 feet without help, a patient with serious dementia is unlikely to improve substantially in his ability to dress independently. Even more sophisticated longitudinal data-checking algorithms could be introduced for follow-up assessments, flagging those records with much more or much less change than might be expected among similar patients. Since nursing homes and home health agencies in many states must submit their clinical assessment data nightly or weekly for proper payment under Medicare and Medicaid, introducing this kind of an "intelligent filter" to flag "suspect" assessments could greatly improve data quality. CMS has explored

the creation of such a tool, but none has been promulgated. Nevertheless, with virtually all nursing homes and home health agencies submitting patient data electronically and with the data being stored in a single repository, it is clearly possible to build systems to apply these kinds of filters and to automatically generate record-specific inquiries back to providers—and perhaps even to maintain an overall measure of data integrity that could be transmitted to the inspection agency.

Several demonstration projects have recently been launched by Quality Improvement Organizations and researchers who have been working to assist CMS in standardizing inspection visits and the resulting data. These projects are part of a larger initiative throughout CMS to expand data-based auditing projects that make it possible to detect "errors" in reimbursement claims and hospital quality reports and to expand other tools that provide follow-up on potential data inconsistency problems in "real time." Numerous private sector companies now offer services to health care providers to help with a host of regulatory, data privacy, and security issues. These systems keep management informed of key operational issues as they arise and are often used to track markers of regulatory and reporting compliance requirements. Whether applied to regulatory inspections or clinical assessment data, periodic on-site "audits" would be a key component of a comprehensive program to improve the uniformity, reliability, and utility of the data on which reimbursements and quality measures are based. These audits could be done on a sample basis in each home, and the results could be used to adjust the measures of quality or even the levels of reimbursement, as has been suggested in the past (Roy and Mor 2005).

Balancing Regulatory Controls and Incentives

Reforming the current regulatory structure for long-term care providers requires that we regulate “smarter” and more consistently, that we improve and maximize the use of the data already being collected, and that we rationalize and integrate the precepts of quality improvement and regulatory oversight in a manner that is transparent and sends a clear message to long-term care providers about the types of experiences frail older persons can expect. To achieve this reform, the fundamental contradiction of the regulator as “cop” or “consultant” needs to be addressed explicitly. In view of the apparent problems that states’ regulatory agencies have in consistently conducting inspections, interpreting rules, and applying sanctions, asking them to also serve an advisory role could exacerbate these difficulties. Since CMS is already willing to invest the QIOs with the resources to advise, stimulate, and direct quality improvement efforts, it may well be that the advisory function should be explicitly adopted by the QIOs. In this way, the QIOs could target quality problems for improvement related to the areas of deficiency identified by the inspectors. Such focused quality improvement would create incentives for nursing homes to increase their involvement with the QIOs.

Provider incentives for fully engaging in quality improvement activities are now being actively tested in “pay for performance” demonstrations. Even if these programs do introduce new revenue to reward providers’ improvement or attainment of certain benchmarks, it is imperative that indicators of performance be reliably measured and that there be a means of establishing priorities for selecting quality performance measures. Since most of the performance measures being considered are based on the aggregated MDS measures, incentive-based reward systems may be premature unless there is general consensus that the data are consistently collected, reliable, accurate and valid.

Chapter VII

Leveraging Health Information Technology

FOR BOTH PROVIDERS AND REGULATORS, a prerequisite for real-time data auditing or data-based clinical care monitoring is state-of-the-art health information technology (HIT). The potential returns on investment for innovation are more significant in HIT than in perhaps any other area. Long-term care, in both home and residential settings, is even more deficient in the application of HIT than the acute care sector. One recent study found that long-term care providers lag behind physician offices and hospitals in HIT adoption across all five functional areas examined (Kaushal, et al. 2005). Although use of electronic claims processing and eligibility determination in long-term care approximates that in the acute care sector, use of electronic results viewing, electronic health records (EHRs), and computerized order entry in hospitals and physician offices exceeds that in skilled nursing facilities and home health agencies; given the relative pace of HIT adoption, this trend is likely to persist for the foreseeable future. This situation is readily remediable, however, with certain policy changes and increased attention, leadership, and investment in integrated HIT at every level of care.

“If we are really serious about moving to a real-time reporting capability, a real ombudsman system, a real ability to shift resources so that we have a collaborative and supportive model of regulatory oversight—rather than an adversarial one—you’re talking about cultural change in these systems that have to have real impact on the management style. More widespread adoption of HIT in long-term care is a prerequisite for any of this to happen.”

—Former Speaker Newt Gingrich,
Commission Co-chair

Where's Long-Term Care?

The recent establishment of the National Coordinator for Health Information Technology marks a concerted national effort to establish electronic health records, instituted with funds awarded to technology standard-setting entities, states, and Regional Health Information Organizations (RHIOs) to implement various data-sharing approaches (U.S. General Accountability Office 2005a). This is certainly a welcome turn of events as, at \$125 million so far, U.S. government investment in HIT has lagged far behind the investments of countries such as the United Kingdom (\$11.5 billion), Germany (\$1.8 billion), and Canada (\$1.0 billion) (Anderson, et al. 2006).

But although major efforts are underway to expand the adoption of EHRs, even into the offices of solo-practice physicians, none of the initiatives funded to date has involved long-term care providers—despite the fact that long-term care providers interface with hospitals on an ongoing basis far more than do most small medical practices. Indeed, nearly one-quarter of long-stay nursing home residents are hospitalized over a six-month period (Intrator, Zinn and Mor 2005), and as many as one-quarter of new admissions to skilled nursing facilities from hospitals are re-hospitalized during their stay (Medicare Payment Advisory Commission 2005a). The numbers are somewhat lower but still quite significant for home health agency patients. If the electronic interchange of critical clinical information could reduce these hospitalizations by even 10 percent, the financial savings would more than offset the cost of building the needed health information bridges. Rather than focusing exclusively on acute and ambulatory care providers, therefore, it behooves federal and state officials to attend to the HIT needs of the long-term care sector as well.

Resources

With HIT, providers frequently wonder whether the juice is worth the squeeze, at least financially. North Mississippi Health Services, a large integrated health system that provides post-acute and long-term care in addition to acute care, has made considerable inroads vis-à-vis HIT, though maintenance costs of \$271,000 annually would likely give smaller providers significant pause (Kramer, et al. 2004). Furthermore, although HIT entails considerable investment by providers (Miller, et al. 2005), 89 percent of financial gains accrue to other stakeholders, payers foremost among them (Middleton, 2005).

In the long-term care sector, there are financial disincentives for hospitals to partner with nursing homes and home health agencies to reduce the rate of hospitalization through HIT—fewer admissions affect the bottom line. There are also non-financial costs limiting provider enthusiasm, the most prominent being the dedication of time, staff, and other resources necessary to learn new systems and stay up-to-date with ongoing changes in hardware and software (Miller and Sim 2005). These concerns are reflected in a 2006 survey, which found that the top IT priority among long-term care organizations in New York State was to implement an EHR system, but that there were major barriers—including the initial expense of IT investment and the difficulty of supporting continuing hardware and software licensing, maintenance, and upgrade costs (Tena-Nelson 2006). Indeed, lack of reimbursement by Medicare and Medicaid is one reason that pioneering organizations have yet to adopt more advanced HIT infrastructures (Kramer, et al. 2004). Unless the federal and state governments provide additional assistance through start-up grants, reimbursement, and continuing support, it may be difficult for some long-term care providers to sustain HIT efforts over the long term.

Coordination

Perhaps the most significant barrier to HIT adoption in long-term care has been the piecemeal development of the HIT infrastructure, which promotes adoption of technologies that cannot speak with one another (Kleinke 2005). Indeed, the goal of interoperability, or the “the ability of a system or product to work with other systems or products without special effort on the part of the customer” (Craft 2005), is the main driving force behind recent governmental efforts to coordinate HIT development.

The importance of coordination cannot be understated. It is one reason that countries with more centralized health care systems have been far more successful in adopting uniform standards than the United States (Shortliffe 2005). It is also the reason that, relative to U.S. health care more generally, the Veterans Health Administration (VHA) has been far more successful in its adoption of interoperable HIT. But even the VHA has yet to adopt systems that can communicate effectively with providers in other settings. This is also true of other technologically advanced health care organizations, which have been unable to overcome barriers to interoperability with unaffiliated post-acute and long-term care entities (Kramer, et al. 2004).

While long-term care providers are increasingly computerizing billing and eligibility determination systems and are even reporting patient-specific clinical and outcomes data in federally-mandated clinical assessments, these systems have virtually no capacity to readily exchange information with the records of affiliated hospitals, labs, pharmacy benefit managers, and—least of all—physicians. This inability to easily transfer information is aggravated by the absence of standard clinical nomenclature relevant to long-term care patients and by long-term care providers’ lack of financial clout with electronic health information systems designers relative to hospitals and large physician practices. Without further government leadership, and without representation of the long-term care industry in the governance structure of federally- and state-funded HIT standard-setting entities, greater interoperability between acute and long-term care providers will be difficult to achieve.

The current lack of HIT adoption and interoperabil-

ity notwithstanding, nursing homes and home health agencies have mandated common clinical assessment and outcomes measurement instruments for nearly a decade. This uniformity should constitute a major advantage since, like hospital diagnoses, the same information can be applied to payment, outcome measurement, and clinical care planning. However, long-term care providers use assessment tools to characterize patients’ functioning that have not been adopted by hospitals or physicians, even though information about older patients’ functioning is far more pertinent than a simple diagnosis.

Not only do EHR designs adopted in the acute care sector lack recognition of long-term care patients’ needs, but the processes of completing government-mandated data sets—even in more technologically advanced long-term care organizations—are distinct from the processes used to maintain electronic health records, which are dominated by medical issues dealing with medications, vital signs, and treatments (Kramer, et al. 2004). Without harmonization of functional information across settings and the adoption of a common framework for assessing patients, interoperability will continue to be impeded by an incompatible lexicon—not just technological challenges.

Regulation

If long-term care providers were working with a common, patient-specific EHR—a uniform set of information on patients’ functional status and care needs in addition to medical information—the data collected would have utility for many audiences and uses. Aggregate data on all patients served by a given provider, for example, could be used to generate reports on operational and quality performance for both internal and external use. This information would place public health officials in a better position to track sudden increases in hospitalizations of frail elders during flu season or rises in new kinds of infections, in addition to helping them determine how many people need evacuation during natural or manmade disasters.

By improving the quality of data used and the processes by which data are assembled, more widespread adoption of HIT would also help address the current lack of uniformity in both regulatory inspections and clinical assessment discussed in Chapter VI. Instead of relying on memory and paper files from multiple, disconnected quality compliance reporting systems, for example, state inspectors could be armed with computerized clinical information about all residents of a facility or about those most “at risk” of experiencing adverse outcomes. Widespread adoption of HIT would also help improve the quality of data employed in federal and state report card efforts, in addition to expanding the parameters of those efforts beyond clinical quality indicators to other areas of importance to consumers. Clearly, there must be more widespread adoption of HIT if we are to move toward a “smarter,” more consistent regulatory process with real-time data auditing and clinical care monitoring capabilities.

“Every night you would know, ‘Did this person get their meds today? Did they lose a pound today? Did anybody notice it? Did they eat?’ An electronic record transmitted to a central source would immediately set off an alarm for all these things, and there could be interventions. It would make a huge difference in terms of the quality of care. It would also create an incredible incentive for the facility to not set off the alarm because they know someone is monitoring them.”

—William Scanlon, Ph.D., Commissioner

Transitions

Increased investment in interoperable HIT systems by hospitals, nursing homes, home health agencies, and others would better enable providers to track patients' care across the all-too-frequent transitions frail elders make between acute and multiple long-term care locations. Each year, more than two million individuals enter nursing homes, and nearly one-and-a-half million receive home care. Because the majority of these people are referred for care following an acute hospitalization, whether at home or in a post-acute facility (Coleman, et al. 2005b; Murtaugh and Litke 2002), transmission of important clinical information is critical to ensure that medical and nursing care can proceed uninterrupted.

Unfortunately, it is rare for such transitions to occur smoothly. Numerous studies reveal high rates of inaccurate or missing information, ranging from diagnoses to a complete listing of a patient's current medications (Coleman, et al. 2005a; Parry, et al. 2003). Research suggests that many patients transferred from hospital to nursing home or paid home care are re-hospitalized a short time later, largely because of gaps in care that occur as a result of missing information in the transfer process (Coleman 2003; Coleman, et al. 2004; Murtaugh and Litke 2002). Research also suggests that both quality and patient safety may be jeopardized among those who remain. These problems are likely magnified among the high percentage of patients who undergo multiple transitions to and from post-acute settings post-hospital discharge (Coleman, et al. 2005b; Murtaugh and Litke 2002).

In recognition of difficulties managing patient transitions, numerous efforts have been made over the past several years to institute a system of expanded clinical information transfer forms—from hospital to nursing home and nursing home to emergency department (Coleman 2003; Coleman, et al. 2004; Davis, Smith, and Tyler 2005). These systems are of varying effectiveness and have been difficult to sustain because they rely on the implementation of new paper records in settings that are already drowning in paper. None involve building electronic data-sharing systems, even though hospitals receive thousands of admissions each year from nursing homes and nursing homes receive the bulk of their referrals from hospitals. Instead,

“Complaints previously voiced by the nursing homes became very real. Medical terms on faxes from hospitals, perhaps decipherable by a physician or advanced practice nurse, were unreadable to most nursing home care providers. Clarifying orders could be frustratingly impossible. If one called the hospital’s main number, the operator no longer had the patient’s name ... If one called the hospital nursing unit ... the nurse answering in the next shift might not know the patient or the discharging physician.”

—M. Nelia Davis, Clinical Nurse Specialist, 2005

patients continue to arrive by ambulance missing transfer forms, medications records, and up-to-date clinical data.

Although most long-term care organizations have yet to develop data-sharing arrangements with hospitals, hospitals are increasingly building information technology systems to integrate inpatient and outpatient records, including those in physicians' offices. Incorporating nursing homes and home health agencies into these networks is clearly possible, but it would require partnerships that have been relatively rare to date. To further the appropriate transfer of essential clinical data, it is critical that long-term care organizations partner with hospitals to overcome barriers to developing and implementing electronic communication systems.

Monitoring

Although few long-term care providers have partnered with hospitals to facilitate the electronic transmission of critical patient information, monitoring devices linked to the telephone have been in use in the homes of elderly and disabled individuals for more than three decades (Dibner, 1992), and new housing is routinely designed with various forms of emergency response systems. A review of these types of tele-monitoring systems for patients with heart failure found that they have been acceptable to patients, have reduced hospital use, and have even positively affected survival (Louis, et al. 2003).

Many different disease-specific technologies that connect patients and their caregivers to home health care nurses and other personnel and automatically transmit physiological information like blood pressure and respiration have been introduced and accepted by individuals living at home (Finkelstein, et al. 2003, 2004; Jenkins and McSweeney 2001). The use of video conferencing, introduced on a limited basis to date, has also been found to greatly enhance the ability of physicians and nurses to manage both routine and acute episodes in nursing homes patients, thereby improving resident outcomes and avoiding unnecessary hospitalizations (Daly, et al. 2005; Laflamme, et al. 2005; Specht, Wakefield, and Flanagan 2001). Along with the data-sharing systems necessary to effectively manage patient transitions, therefore, further integration of cutting-edge tele-monitoring technologies into long-term care settings should be encouraged.

Toward Increased HIT in LTC

It is critical that the nation include long-term care in health care innovation by designing an HIT infrastructure that incorporates nursing homes, home health agencies, and other long-term care providers. The ingredient missing so far has been leadership, without which the diffusion of HIT into long-term care has foundered. Leadership may involve inclusion of long-term care industry representatives in the governance structures of both state and federally-funded standard-setting entities. Also essential are increased investment in HIT applications in long-term care and the incorporation of long-term care patient needs into initial EHR designs. The result should be more valid and reliable data with which to improve consumer report cards and regulate “smarter” through real-time data auditing and clinical care monitoring. And broader HIT adoption should spur hospitals, nursing homes, and other long-term care providers to form partnerships to promote greater investment in interoperable HIT systems that—through the seamless transfer of patient-level data from one care setting to another—reduce errors, improve quality, and better monitor patients.

Epilogue

“I HAVE WORKED IN LONG-TERM CARE for nearly 50 years, beginning with the first White House Conference on Aging in 1961. For a long time, I have believed that the field is so politicized internally that virtually no productive conversation takes place among the current actors—for-profit versus not-for-profit, home care versus institutional care, advocates versus providers. There needs to be something that is above the fray, helps frame the policy questions in a way that is not self-serving, and takes into account the demographic and economic realities facing society. It is critical that people—all of us—learn about the major issues that deserve stakeholders’ attention, and about the options and alternatives available for addressing these issues. But if there were one single thing that could be brought to the attention of the American public, and to the attention of all decision-makers, it is this: unless we do something now, we’ll one day reach the point where we have lots of people who are very poor and very frail and who have very little support. We can do better.”

—Monsignor Charles Fahey, Commissioner

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