NATIONAL COMMISSION FOR
QUALITY LONG-TERM CARE

Final Report

FROM ISOLATION
TO INTEGRATION

Recommendations to Improve Quality in Long-Term Care

December 3, 2007

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Recommendations to Improve Quality in Long-Term Care

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The Commission would like to acknowledge the work of Geralyn Graf Magan, whose writing and editorial assistance has enabled the Commission to summarize its work and express its members' diverse opinions in a single, comprehensive document.

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OVERVIEW

The population of the United States is heading toward a dramatic and unprecedented demographic shift. Well into this century, the number of older Americans will grow substantially with each passing decade as the average person lives longer than we ever imagined possible. As a result, the nation will experience an unprecedented demand for high-quality long-term care services provided in a wide variety of settings, including private homes, assisted living facilities and nursing homes. Unless we take action in the near future to prepare for these changes, our nation will not be ready and, inevitably, many of our citizens will suffer.

The National Commission for Quality Long-Term Care calls for a bold, national discussion about how the United States can create a new and better long-term care system that will help older people and people with disabilities remain independent for as long as possible. The Commission calls on the Congress of the United States to hold hearings during 2008 that will investigate and recommend workable strategies to design and implement that system. The Commission also urges the next President of the United States to provide the leadership necessary to launch a multifaceted transformation of long-term care so that it:

- Places the needs and preferences of consumers at the heart of every care setting and fosters the right of those consumers to make care and lifestyle decisions for themselves.

- Provides adequate supports for family caregivers, without whom the nation could not care adequately for its aging citizens and citizens with disabilities.

- Ensures that long-term care workers receive the training, compensation and respect they need to provide compassionate, high-quality care.

- Adopts emerging technologies that will help maximize the independence of older consumers and make care provision more efficient.

- Institutes a financing system that utilizes public and private resources to ensure that every American who needs quality long-term care will have access to those services.

INTRODUCTION

The population of the United States is heading toward a dramatic and unprecedented demographic shift. Well into this century, the number of older Americans will grow substantially with each passing decade.[1] The average person will live longer than we ever imagined possible.[2] As a result, the nation will experience an unprecedented demand for high-quality long-term care services provided in a wide variety of settings, including private homes, assisted living facilities and nursing homes.

Unless we take action in the near future to prepare for these changes, our nation will not be ready and, inevitably, many of our citizens will suffer. That very real possibility is raising the anxiety level of many Americans, who are already worried about the quality, affordability and availability of acute and long-term care.

The current presidential campaign has focused needed attention on our broken health care system. Long-term care now deserves equal attention from the candidates, from the nation's state and federal legislators, from its governors and from the White House. It is critically important that policy makers at all levels of government understand that there will be no real solution to the health care crisis without a complementary solution to the long-term care crisis, and vise versa. Neither crisis can be addressed in isolation.

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[1] An analysis of Census figures by the Administration on Aging suggests that the population 65 and over will increase from 35 million in 2000 to 40 million in 2010 and then to 55 million in 2020. By 2030, there will be about 71.5 million older persons, almost twice their number in 2005. People 65+ represented 12.4 percent of the population in the year 2005 but are expected to grow to be 20 percent of the population by 2030. The 85+ population is projected to increase from 4.2 million in 2000 to 6.1 million in 2010 and then to 7.3 million in 2020. Source: Administration on Aging. 2006. *A Profile of Older Americans: 2006*. Available at: http://www.aoa.gov/prof/statistics/profile/2006/2006profile.pdf.

[2] The U.S. Census Bureau predicted this spike in longevity almost a decade ago, when it reported that the number of American centenarians had nearly doubled, to 70,000, during the 1990s. Bureau analysts predicted at the time that if this doubling-per-decade trend continued over the next several decades, almost a million Americans would be living past 100 by the middle of the 21st century. Source: Krach, C., Velkoff, V. 1999. *Centenarians in the United States: 1990*. Washington, DC: U.S. Census Bureau.

Like the nation's health care system, the long-term care system begs for transformation. Demographic changes over the next 20-30 years will pose entirely new challenges to long-term care and meeting those challenges will require new approaches to serving long-term care consumers. Thirty years may seem like a long time to get ready to face these challenges and we may be tempted to adopt a wait-and-see attitude concerning the impact that a growing aging population will have on long-term care. That attitude would be dangerous. True long-term care transformation will take time if it is going to be effective and sustainable. To ensure success, we must start work *now*.

With this report, the National Commission for Quality Long-Term Care calls for a national discussion about how we can create a new and better long-term care system. The Commission calls on the Congress of the United States to hold hearings during 2008 that will investigate and recommend workable strategies to design and implement that system. The Commission also urges the next President of the United States to provide the leadership necessary to launch a multifaceted transformation of the long-term care system so that it will be able to serve consumers for decades to come. This transformation cannot take place only at the local or state levels; instead, we need *national* solutions to the long-term care crisis so that all Americans, no matter where they live, can benefit from the system's reform. That reform must ensure that long-term care:

- Places the needs and preferences of consumers at the heart of every care setting and fosters the right of those consumers to make care and lifestyle decisions for themselves.

- Provides adequate supports for family caregivers, without whom the nation could not care adequately for its aging citizens and citizens with disabilities.

- Ensures that long-term care workers receive the training, compensation and respect they need to provide compassionate, high-quality care.

- Adopts emerging technologies that will help maximize the independence of older consumers and make care provision more efficient.

- Institutes a financing system that utilizes public and private resources to ensure that every American who needs quality long-term care will have access to those services.

Background on the Commission

In September 2006, the National Commission for Quality Long-Term Care initiated a long-overdue national dialogue about what actions this country could take *today* to transform the long-term care system of tomorrow. In a document entitled *Out of Isolation: A Vision for Long-Term Care in America*, we promised to devote our energy to creating a roadmap for comprehensive reform of the often-fragmented system that serves and supports Americans with disabilities as they attempt to carry out basic activities of daily living.

In our 12-month effort to carry out this promise, the Commission has conferred with a variety of experts: researchers who have thought long and hard about the issues affecting the field of long-term care; advocates representing the interests of older people, who comprise the majority of long-term care consumers; and long-term care providers, who have seen firsthand the flaws in long-term care and are working hard to correct those flaws.

This, the Commission's final report, is the culmination of that effort. The following pages present our best thinking, and the best thinking of the experts with whom we consulted, about what "next steps" the nation needs to take to build a compassionate, high-quality and economically sound long-term care system of which all can be proud.

Long-Term Care: A Pressured System

Each day, almost 10 million Americans with disabilities, ranging in age from children to older adults, use long-term care services that allow them to carry out daily activities that most of us take for granted. Living in their own homes or in such residential settings as assisted living facilities and nursing homes, these Americans require assistance with such private activities as bathing, eating, dressing or using the toilet — and such essential daily

tasks as shopping for groceries, preparing their meals, managing their medications or keeping their homes clean.

We all know at least one of these Americans. He or she may be a young cousin born with cerebral palsy or an adult brother or sister coping with multiple sclerosis. But most likely, the long-term care consumers we know best are our own mothers, fathers, aunts and uncles: people who enjoyed full independence until a stroke, hip fracture, the onset of dementia or another disease associated with aging compromised their health or brought on disability and frailty.

About two-thirds of long-term care consumers are 65 years or older, a sobering statistic for the oldest members of the Baby Boomer generation, who will begin to reach this age in a matter of years. While few of these Baby Boomers will need long-term care services for at least a decade after they turn 65, the fact that so many members of this large generation will need care at the same time has provided the nation with an important "wake-up" call. Clearly, it's time to begin planning ahead for the impact these aging Americans will eventually have on the long-term care system. Especially sobering for the future is the fact that half of all Americans 85 years and older find themselves in need of long-term care services. The 85+ population is projected to increase from 4.2 million in 2000 to 6.1 million in 2010 and then to 7.3 million in 2020.[3] It is prudent to assume that as the number of very old people increases, so will their demand for high-quality long-term care services.

Media outlets interested in the sociological effects of an aging population are helping to make average Americans generally aware of what this predicted population growth will mean, on so many levels, for our country. But it remains the challenging work of care providers, policy makers, researchers and aging advocates to develop and champion a national strategy to ensure that the long-term care system will be capable of serving this population, and serving it well. This is a tall order, particularly because the current long-term care system is already operating under great pressures:

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[3] Administration on Aging. 2006. *A Profile of Older Americans: 2006*. Available at http://www.aoa.gov/prof/statistics/profile/2006/2006profile.pdf.

- ***Consumers are under pressure.*** Most people will come to long-term care after the onset of disability, whether that disability presents itself at birth, after a trauma or as a result of diseases associated with aging. Older persons who need help with daily activities must learn to cope with many losses, including a loss of independence, of income and assets, of community connections and sometimes of their homes. In addition, many older people with disabilities find themselves in the untenable position of having declining income and savings at the same time when disability-related expenses are mounting. This confluence of challenges brings with it a harsh reality: many older people with disabilities simply do not have the financial resources to obtain the services they need, either in the community or in long-term care facilities. In some cases, their care options are limited, if available at all.

- ***Families are under pressure***. Family members, who provide the bulk of long-term care services, face many challenges when an older relative requires assistance with daily activities. These unpaid caregivers deserve our admiration for their willingness to care for their loved ones, often at great risk to their own health and well-being. Yet in return, they receive little information, training, financial assistance, respite or professional services to support them in their caring work.

- ***Long-term care providers are under pressure***. Providers feel increasing pressures to deliver high-quality long-term care services. Yet, many providers maintain that inadequate funding makes it difficult for them to upgrade their infrastructures and their care practices. In particular, providers say that they lack the necessary resources to recruit, train and retain quality staff, especially those direct care workers who provide day-to-day care to long-term care consumers. These workers are in short supply, in large part because their demanding jobs don't offer adequate salaries, benefits, training or opportunities for advancement.

- ***Government agencies are under pressure.*** Understaffed agencies, charged with measuring and ensuring the quality of long-term care services, struggle to enforce

regulations that are sometimes poorly designed and that often allow mediocre providers to survive while failing to reward innovative ones. State Medicaid agencies, which fund long-term care services in partnership with the federal government, must stretch their limited budgets among competing interests, including acute care and long-term care provided in institutions and home settings. For their part, state and federal policy makers also face competing pressures to keep taxes low while providing adequate funding for a host of government services, including health and long-term care.

Encouraging Signs

Over time, these pressures have served to undermine the long-term care system and to compromise its ability to provide quality of care and quality of life to the oldest and frailest of our citizens. Yet, we're now seeing some hopeful signs that the development of comprehensive strategies to improve quality is becoming a new priority for a growing number of long-term care consumers, providers, government regulators, funders and policy makers. In recent years, these stakeholders have renewed their efforts to regain the public's trust by taking steps that could lead to a complete transformation of the very culture of long-term care. That transformation, if successful, will mean that quality improvement, consumer direction and a collaborative spirit will eventually become the focal point of every care setting.

In 2002, three major provider organizations in the long-term care industry — the Alliance for Quality Nursing Home Care, the American Association of Homes and Services for the Aging and the American Health Care Association — adopted a voluntary initiative called "Quality First" to improve the care their members provide. In a fitting complement to this provider initiative, the U.S. Department of Health and Human Services (HHS) launched the Nursing Home Quality Initiative and the Home Health Quality Initiative that same year. Both of these HHS initiatives focus on developing strategies to promote quality in long-term care settings and to make quality information available to the public.

Long-term care stakeholders soon began to recognize that the nation needed an autonomous body that could take an objective and holistic approach to long-term care reform. To meet this need, the National Commission for Quality Long-Term Care was convened in October 2004 by the National Quality Forum, a Washington-based, not-for-profit member organization created to develop and implement a national strategy for health care quality measurement and reporting. The Commission was charged with (1) evaluating the quality of long-term care, (2) identifying factors influencing the ability to improve that care and (3) making recommendations about national efforts that could lead to sustainable quality improvement. Three years later, the Commission continues its work at The New School, a New York-based university that pursues an organizational mission to prepare and inspire undergraduate and graduate students to bring actual, positive change to the world. Funding for the Commission is provided by the Alliance for Quality Nursing Home Care, the American Association of Homes and Services for the Aging and the American Health Care Association.

Reasons for Optimism

As members of the Commission, we believe that a rational and efficient long-term care system can be built. This belief is not based on a Pollyanna-like optimism that has no basis in reality. Indeed, as former and current governors, members of Congress, state officials, policy experts, aging advocates, journalists, physicians and health care industry leaders who have been involved in long-term care issues for decades, we are, above all, realists.

We have personally investigated and heard credible reports about long-term care providers who, for reasons of greed or incompetence, have inflicted harm on our older citizens through inferior, mediocre or downright dangerous care practices. In light of this knowledge, what has convinced us to continue believing in the efficacy of long-term care reform? We have also seen the long-term care system work — and work well. We have met and observed the work of conscientious providers who collaborated with their care staffs, and with policy makers, regulators, long-term care consumers and their families, to create quality care environments. Those environments respect the wisdom and worth of every person who lives

there. They also ensure, each and every day, that the lives of long-term care consumers are characterized by security, fulfillment, enjoyment, dignity and self-direction. To us, seeing what is possible has meant believing that we can make a difference.

Over the past 12 months, members of the National Commission for Quality Long-Term Care have chosen to focus our attention, not on the flaws that we know exist in long-term care, but on the quality environments that have given us hope. We have examined policies and practices that have encouraged long-term care providers to design and implement the kind of high-quality services that we ourselves would purchase for our mothers and fathers, and for ourselves when the time comes. We place our hope in these emerging models of care, oversight and financing, many of which are described in these pages. We urge the nation to take actions that will cultivate these and other effective models so they can be adapted and adopted by care settings and policy makers throughout the country.

Purpose and Structure of This Report

The National Commission for Quality Long-Term Care has translated its discoveries and analyses over the past 12 months into a set of recommendations that address three specific aspects of long-term care delivery: quality, workforce and technology. These recommendations are contained in the first three chapters of this report. In Chapter 4, the Commission presents a framework and general principles that address the important area of financing long-term care. Commission members believe that these recommendations and principles can serve to move the nation forward in its efforts to reform long-term care:

- **Quality**: We can reform long-term care by transforming its culture through organizational and caregiving innovations that focus on improving both individuals' quality of life and their quality of care. In addition, we can better support the millions of informal caregivers by providing them with respite care, information and assistance.

- **Workforce**: We can reform long-term care by offering tangible support — in the form of improved compensation, better working conditions, training and opportunities for

advancement — for formal caregivers who provide direct care to frail and vulnerable older people.

- **Technology**: We can reform long-term care by developing and using emerging technologies that promise to enhance consumer independence and promote better quality of care while safeguarding consumers' privacy and autonomy.

- **Finance**: We can reform long-term care by creating a financing system that ensures that the costs associated with chronic disease and disability will be shouldered equitably by individuals and the public sector, and that all Americans can have access to high-quality care and services that will help them live independently for as long as possible.

Each of the Commission's three sets of recommendations is preceded by a brief overview. The overviews are based on several papers presented to the Commission during 2007 by experts in the field. To obtain more information about a particular issue area, readers are invited to view these papers, which are available for download at the Commission's Web site, www.ncqltc.org. They include:

- *Long-Term Care in America: An Introduction,* presented in January 2007 by Anne Tumlinson and Scott Woods, Avalere Health LLC.

- *The Long-Term Care Workforce: Can the Crisis be Fixed? Problems, Causes and Options,* presented in January 2007 by the Institute for the Future of Aging Services.

- *Strategies for Improving the Quality of Long-Term Care*, presented in April 2007 by Joshua M. Wiener, PhD, Marc Freiman, PhD, and David Brown, MA, RTI International.

- *Essential but Not Sufficient: Information Technology in Long-Term Care as an Enabler of Consumer Independence and Quality Improvement,* presented in September 2007 by Ross D. Martin, MD, MHA, David Brantley and Darcy Dangler, BearingPoint, Inc.

An Integrated Approach to Reform

The Commission believes strongly that action in the areas of quality, workforce, technology and finance is required if the level of quality in long-term settings is to increase measurably. We recommend that policy makers, providers and other stakeholders focus their attention equally on all four issue areas. Because these areas are interconnected on a variety of levels, our successes or failures in one area will affect every other area. For example:

Our nation's success at improving quality of care and service in long-term care will depend on our ability to develop and enforce quality care standards … *and* our ability to recruit, train and retain quality staff people to provide that care … *and* our ability to use technology to provide accurate data that are essential to quality assessments.

Our nation's success at developing an adequate supply of caregivers will depend on our ability to invest additional money in staff salaries, benefits and training for formal caregivers … *and* our support for informal family caregivers who provide the vast majority of direct care to people with disabilities … *and* our ability to use new technology to ensure that staff members work more efficiently and effectively … *and* our ability to create quality care settings where professionals and direct care workers will want to work.

Our success at incorporating technology into both home care and institutional care will depend on our ability to bring new dollars into long-term care settings … *and* our ability to let quality-driven principles such as consumer independence, autonomy, privacy and choice guide our technical efforts … *and* our ability to train staff at multiple levels of long-term care organizations to make the best use of the technology at their disposal.

We could list many other examples of the interconnectivity of long-term care issues. But our point should be clear: the individual recommendations and principles included in this report cannot be viewed in isolation. Long-term care, at its best, cares for the entire person and takes an integrated approach to that person's care. Efforts to reform long-term care require an equally integrated approach.

Conclusion

A year ago, the National Commission for Quality Long-Term Care characterized the reform of long-term care as a moral, financial and social imperative. We still feel that way. This nation can no longer depend on the old ways of doing things — those ways haven't worked for many years. Instead, we need to take positive and deliberate steps — and we need to take them together — to create a new day in long-term care. Our goal is to create a future in which older consumers and their families will use long-term care services, not with a sense of dread and foreboding, but with sincere gratitude that when they most need help, high-quality care in a caring environment is available to them. The Commission presents this report, and its recommendations and principles, with that new day in mind.

CHAPTER 1: QUALITY[4]

Gather a group of 20-30-year-olds at a party or other social function, the old story goes, and inevitably these young adults will begin chatting about a variety of topics, including their respective careers and their growing families. Gather a group of 40-, 50- or 60-year-olds together at a similar function, on the other hand, and the conversation will inevitably turn to the one emotion-packed topic that affects nearly everyone in the room: their aging parents and the multilayered challenges involved in accompanying those parents on their journey through the aging process. Inevitably, the conversation will also turn to the aging processes, disabilities and conditions that these Baby Boomers and their friends are experiencing, as well as some expressions of their own care preferences should they find themselves in need of assistance in the future.

The journey into old age can be fulfilling and especially meaningful for older people who remain actively engaged in their communities and families. But when illness or disability interferes, the journey can often become a painful and emotional one for parent and child alike. For older persons, frailty can bring with it difficult and life-changing decisions about housing and lifestyle, the need for courageous determination to live fully in spite of physical or mental limitations and, ultimately, the very-real fear of dependence and irrelevance. For middle-aged Baby Boomers, seeing once-strong parents experience physical and mental declines can bring sadness and worry over an older parent's well-being and safety, as well as fatigue and stress brought on by the rigors of providing direct care.

For both parent and child, the aging process may also eventually bring with it the need for assistance with routine daily tasks. Initially, caring family members will typically provide most, if not all, of the long-term care services that an aging relative requires. However, older

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[4] Unless otherwise noted, the information presented in this overview is taken from *Strategies for Improving the Quality of Long-Term Care,* a paper presented to the Commission in April 2007 by Joshua M. Wiener, PhD, Marc Freiman, PhD and David Brown, MA, RTI International.

persons overwhelmed by growing needs or concerned about the burden on family members may eventually prefer to seek other alternatives. That's when questions about long-term care quality — how to judge it and where to find it — become critically important and frustratingly difficult to answer.

In the best-case scenario, the quest for long-term care services begins at home, when older consumers plan in advance for frailty and take steps to ensure that their home's physical layout and other features can continue to support them even as their needs increase. The planning process may next involve researching, choosing and managing in-home services to supplement the informal help that the consumer already receives from friends and family members. Or, it may include searching for a different living environment altogether — possibly supportive housing, assisted living or skilled nursing care — where older persons can receive the care and/or services they need in an environment where their involvement in care and lifestyle decisions is encouraged and respected. In some cases, unfortunately, these options will be limited, if available at all.

No matter what choices the older consumer makes, there's no arguing that aging well is hard work. It's challenging, for example:

- To understand the myriad long-term care options, especially if the goal is to maximize independence for as long as possible; or to confront the reality that there is a dearth of services, particularly in small, rural communities.

- To locate appropriate care and services in the right setting and at an affordable price.

- To pay for those services.

- To conduct the level of research and due-diligence necessary to reassure older consumers that the services they have chosen are of the best quality available.

Unfortunately, that last challenge — feeling confident about quality — is often the hardest one to master. And no wonder. Providers, regulators and policy makers have struggled for years to ensure that consistent high-quality of care is provided in a variety of settings. In the process, those stakeholders have asked critical questions, over and over again, about what quality means and what specific features are present in high-quality long-term care programs and services. More broadly, they have sought to discover how the nation can go about ensuring that all long-term care consumers experience high-quality care and enjoy the highest possible quality of life no matter how many long-term care services they receive or where they receive them. These questions bear repeating today. As the United States gears up for an unprecedented increase in the number of its older citizens, the need to define and ensure high-quality care and services is great.

Measuring Quality of Care and Quality of Life

Over the years, the most piercing questions from regulators and policy makers about long-term care quality have been spurred by scandal. In the 1980s, for example, the Institute of Medicine identified widespread concerns about quality in nursing homes, and Congress subsequently enacted the landmark Omnibus Budget Reconciliation Act of 1987 (OBRA), which raised quality-of-care standards and strengthened federal and state oversight of nursing homes participating in Medicare and Medicaid. Since then, the level of quality in nursing homes has been measured in a number of very specific and objective ways. For example, nursing homes literally count the number of residents who are *not* receiving good quality care because these residents are, for example, being restrained physically or chemically, have pressure sores or dehydration, or are using urinary catheters. Decreases in these and other troubling practices and incidents have been among the nation's best and most concrete indicators that nursing home residents are receiving more attention and better care as a result of OBRA.

As might be expected, however, OBRA did not turn out to be the "magic pill" that would cure all the quality concerns that ailed nursing homes. Many facilities continued to operate with serious deficiencies after 1987 and the new system didn't always succeed in forcing

troubled facilities to correct those deficiencies. In a dramatic, albeit anecdotal, indication of the work that still needs to be done to improve quality, some older people have continued to tell researchers, decades after OBRA became law, that they would rather die than go to a nursing home.

Do deficiencies and the continued poor reputation of nursing homes suggest that objective quality standards and measurements like those included in OBRA are ineffective? Not at all. OBRA has improved nursing home quality, but there is still significant room for *more* improvement. Primarily, the effectiveness of OBRA has been marred not by a flaw in the intent of the law, but by a failure to adequately implement the standards it promulgated. Specifically, OBRA's effectiveness has suffered from an inspection system that all too often either does not detect violations or, when violations are detected, does not guarantee that those violations will be promptly corrected. This situation can and must be corrected if consumers are to feel confident that they will receive high-quality, long-term care.

Administrative inefficiencies are not the only reason quality problems have persisted in long-term care. Indeed, consumers, scholars and policy makers have all raised questions about whether objective standards by themselves can ever present a complete picture of whether a residential facility is high-quality. As more consumers voice their preference to receive care in home-based settings, regulators and policy makers will also have to ask similar questions about how to assess whether a home-care setting, which is not governed by OBRA, is high-quality. One answer to those questions has been a new movement called "culture transformation," which suggests that another type of standard is needed in both home and institutional settings that would complement objective evaluations of *quality of care*. That less-objective standard would evaluate and measure *quality of life*.

Transforming the Culture of Long-Term Care

Any consumer who has attempted to evaluate the quality of something as simple as a restaurant meal, a hotel room or even the latest best-selling novel knows how imprecise that process can be. Certainly there are concrete elements of a meal, room or novel that can be

evaluated objectively and translated into recommendations for friends and family. A diner, for example, can report on the apparent freshness of a restaurant's food or on the promptness of its service. A traveler can examine the firmness of the hotel mattress or the cleanliness of the bathroom. And the reader can objectively assess the technical expertise of the writer when deciding what grade to give a particular book.

These largely objective assessments can help consumers draw certain conclusions about the quality of their individual experience. But those conclusions won't be completely accurate unless consumers include that vague, but no less valuable, sense of how the product or experience made them *feel*. Did the meal give the diner pleasure? Did hotel staff make the traveler feel welcome and at home? Did the book entertain or inspire?

The same multilayered evaluation process can and should be applied to long-term care. Up until now, some suggest, long-term care regulators have placed too much emphasis on measuring the firmness of that hotel bed, so to speak. By focusing only on *quality of care*, these regulators have been evaluating only those practices that can be measured by counting restrained residents or cataloging bad outcomes, among other quality indicators. While these are important measures that can't be ignored, they also don't tell the entire story about quality.

Granted, long-term care has definite *medical* aspects that need to be measured in objective ways. But because long-term care also provides *social* aspects of care — care with which older people must live 24 hours a day for long periods of time — a critical component of quality provision and evaluation must also include attention to the resident's *quality of life*. Like the diner, traveler and reader, consumers of long-term care can tell us how their care makes them *feel*. Consumers can also tell us if their care helps them live the kind of life they want to live.

Measuring quality of life means asking essential questions about the lives of long-term care consumers — questions that aren't typically found on a surveyor's checklist. They include:

- Do residents in long-term care facilities and consumers of home and community-based services feel in control of their lives?

- Are these consumers allowed to participate in care decisions?

- Do these consumers feel engaged in the life of their communities?

- Are these consumers comfortable where they live and do they feel at home there?

- Do these consumers feel safe and well cared for, and do their caregivers make them feel valued as human beings?

- Do care providers do their utmost to preserve the consumer's dignity?

These questions shed light on the essential elements of a satisfying and meaningful life — elements that should not and cannot be denied to older people simply because they require long-term care services. Of course, answering "yes" to these questions can be a challenge for long-term care providers. In spite of these challenges, however, more and more providers are making that "yes" their goal.

For some community-based service providers, getting to "yes" has meant creating a diverse collection of home and community-based services (HCBS) that strive to keep older people from ever having to move to formal care settings. These services include home health care, hospice, adult day services, transportation, senior centers and assistance for family caregivers. They are specifically designed to acknowledge and support the overwhelming desire of older people to remain, for as long as possible, in their own homes where they can live on their own terms, make their own care decisions and direct that care on a day-to-day basis. HCBS providers have made great strides in building strong service networks within communities around the country but more work is needed to enhance the services available to community-dwelling older people, to improve the efficiency and quality of that service

delivery and to increase the amount of support available to family caregivers, who provide the bulk of long-term care services that older people receive in their own homes.

To ensure that dignity and autonomy don't disappear when older consumers leave home, some providers of facility-based long-term care services are working hard to transform the entire culture of their organizations — including their physical settings — so that those facilities feel more like "home" in every sense of the word. These providers have made a commitment to preserve the privacy, dignity, autonomy and choice of their residents. They deliberately deemphasize the hierarchical, medical and bureaucratic features — the provider-centered features — that have dominated long-term care settings for so many years. They give renewed attention to making sure that every aspect of facility design and operation reinforces the organization's goal to place the consumer — and his or her preferences and desires — at the heart of every care decision.

Notable examples of these transformative models can be found throughout the country and include the Eden Alternative, the "Green House" movement and the Wellspring Model. Together, these models are breathing new life into long-term care facilities by strengthening the ties between residents and the greater community; by creating smaller facilities or smaller units within large facilities that present a truly homelike environment where residents make their own decisions about how they will spend their time; by training direct care workers so they feel both competent and valued; by using long-term staffing assignments to encourage those workers to develop long-term relationships with residents; and by empowering staff members to work with residents to make care decisions. To date, the results of this consumer-centered approach to long-term care have been encouraging, with documented evidence of more satisfied and empowered residents, better care outcomes, better quality scores on regulatory surveys, reduced staff turnover and, in some cases, reduced costs. Long-term care consumers and the quality of long-term care services seem likely to benefit from more widespread adoption of these basic quality-of-life principles in all settings.

Reality Check

Transforming the culture of long-term care is a worthy goal and one that all long-term care providers should be encouraged to pursue. But make no mistake. The process of transforming long-term care is much more complicated than simply embracing a popular new model of care. The difficult truth is that no one model can solve all of the problems; no one model can serve every segment of the population; and no one model can be adopted widely without affecting myriad other aspects of long-term care, including its regulation and financing.

A true transformation of long-term care — one that is consistent with an overall commitment to consumer choice — is likely to be messy. Providers and policy makers will need to sit down with consumers and their families, *really* listen to consumer needs and desires and work hand-in-hand with consumers to design a better long-term care system. All stakeholders — providers, lawmakers and consumers — will need to make tough decisions and agree to compromises about where money can be invested most wisely in order to create inviting, empowering and high-quality long-term care environments. Regulators, consumer advocates and providers will need to explore together the regulatory issues that the transformation process will inevitably raise. These issues, many of them controversial, will not be resolved overnight, nor will providers, policy makers, regulators, consumers and their families find it easy to reach consensus. However, the Commission believes that the process of building a consumer-centered long-term care system, however difficult, is worth the intense effort that it will require.

Reforming the System

Having meaningful care standards "on the books" is an important and obvious first step in the process of ensuring quality long-term care, whether that care is provided in traditional or "transformed" settings or in the home. But the real test of any quality standard is its ability to actually improve the care and services that the nation's long-term care consumers receive each day. In 2005, the U.S. Government Accountability Office (GAO) found that the

OBRA quality standards appeared to have done their job in this regard. After studying data from state inspectors and surveyors, the GAO concluded that there had been a significant decrease in the proportion of nursing homes with serious quality problems in the prior six years, from about 29 percent in 1999 to about 16 percent in January 2005.[5]

This decrease in serious quality problems is a good sign and a step in the right direction. But it is not the end of this story. The GAO findings also mean that serious quality problems are still leaving residents in 16 percent of nursing homes at risk. This situation is clearly unacceptable and requires that regulators take rapid, aggressive steps to enforce standards more effectively.

The GAO has noted nursing home quality enforcement problems for several years. For example, its 2005 investigation found inconsistencies in how state surveyors were conducting their nursing home inspections and raised concerns that surveyors were understating the serious deficiencies they found. In addition, delays in the reporting and investigation of serious complaints, and an inadequate system to ensure that identified deficiencies were addressed and corrected, created doubts about whether the carefully crafted survey process was fulfilling its mission in all circumstances. A follow-up study released by the GAO in March 2007 indicated that enforcement policies at the Centers for Medicare and Medicaid Services (CMS) allow some homes with the worst compliance histories to escape immediate sanctions designed to punish them for putting residents at risk.[6] Given this poor record, it is not surprising that in 2005 the Administration on Aging's (AoA) national long-term care ombudsman reporting system reflected more than 230,000 consumer complaints in the prior 12 months concerning quality of care and quality of life.[7]

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[5] U.S. Government Accountability Office. 2005. *Despite Increased Oversight, Challenges Remain in Ensuring High-Quality Care and Resident Safety* (GAO-06-117). Washington, DC: U.S. Government Accountability Office.

[6] U.S. Government Accountability Office. 2007. *NURSING HOMES: Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents* (GAO-07-241). Washington, DC: U.S. Government Accountability Office.

[7] Administration on Aging. 2005 National Ombudsman Reporting System Data Tables. www.aoa.gov/prof/aoaprog/elder_rights/LTCombudsman/National_and_State_Data/2005nors/2005nors.asp.

It's clear from these findings that, despite the progress we've made over the past two decades, the nation is not yet "there" when it comes to ensuring quality in long-term care. Indeed, we have much more work to do in many areas. First, as mentioned earlier in this chapter, we need to transform long-term care so that every care setting preserves the privacy, dignity, autonomy and choice of its residents and places consumers and their preferences and desires at the center of every care decision. Next, we need to give our attention to the following areas: strengthening existing quality standards, improving the quality of home and community-based settings, empowering consumers, encouraging providers to take responsibility for quality care, supporting family caregivers who provide the bulk of long-term care services and focusing attention on the need for high-quality end-of-life care.

Strengthening Existing Quality Standards

Long-term care consumers and their advocates are calling for better ways to enforce the current system of quality standards so deficiencies will be reported and corrected in a timely manner. We need to take steps immediately to strengthen the system we have created to enforce quality standards in nursing homes. In addition, we need to take a new look at how standards for quality of life can be incorporated into our survey system. No one denies that quality of life is a desirable characteristic for which long-term care should strive. However, defining and regulating such quality could be difficult and could raise controversial issues about how to provide consumers with more choices while continuing to protect them from harm. These issues need to be addressed adequately before any workable system can be put into place. It is also important to examine measures used in different long-term care settings to determine if additional or improved measures or data might be needed.

Improving the Quality of Home and Community-Based Services

The movement toward home and community-based services, expanded in the past decade through Medicaid's HCBS waiver programs, has been based on the assumption that long-term care services provided at home can be better and more satisfying to the consumer than institutional care. Home and community-based services have great potential to provide valuable long-term care in a less restrictive environment while offering consumers an

invaluable sense of independence, autonomy and control. People who use home care typically *do* report high levels of satisfaction. The Commission believes strongly that consumers and their caregivers are usually the ones who can best evaluate the quality of the services and support they receive. However, some regulatory interventions may be needed to set standards and guidelines regarding what constitutes good quality in home and community-based settings. These standards can guide both providers and consumers in designing and evaluating services.

Regulating home care carries its own practical challenges, since that care is provided in diverse settings. In addition, the recent emphasis on consumer-directed care will also require that regulators ask new and probing questions about how and to what extent HCBS quality should be measured, and if a consumer's power to hire, schedule, direct, monitor and fire care workers will, in and of itself, improve quality in the home-care marketplace. Some answers to those questions can be found in the Cash and Counseling initiative, a concept developed with funds from the Robert Wood Johnson Foundation, which allows consumers to hire, schedule, direct, monitor and fire care workers. Research on the program has found that participants report a higher quality of life and fewer unmet needs.

Older people who are fully capable of exercising their power in the marketplace may be able to guarantee quality care for themselves. However, regulators and policy makers may need to step in to protect consumers who have serious illnesses or disabilities, have cognitive impairments or dementia, or are making care decisions in the midst of a crisis or without families to help them. Policy makers will also need to weigh the benefits of regulating home-based care against the risks of stifling innovation, imposing a medical model, raising costs and limiting choice.

Empowering Consumers

Older consumers and their families can play a central role in fostering improved quality in long-term care settings. However, in order to fill that role, consumers need to be well-informed about standards of quality in long-term care; they also need to know what questions to ask about a provider's quality record and how to best use their power in the

marketplace to reward well-performing providers with a generous market share and penalize poor-performing providers by shunning their services.

Consumer power to bring about change in long-term care is directly related to the availability and accessibility of good, clear and comprehensive information about standards of quality and providers' records in meeting those standards. Actually, a wide variety of data sources do exist that could improve consumers' ability to purchase high-quality care. For nursing homes, that data can be gleaned from the Minimum Data Set (MDS), which includes functional and medical information on all residents; or the Online Survey, Certification and Reporting (OSCAR) system, which provides data collected by onsite surveyors who inspect nursing homes for Medicare and Medicaid. Additional information related to quality issues is available from the AoA's Ombudsman Program, which receives and investigates consumer complaints about care, and from the Nursing Home Consumer Assessment of Health Plans Survey, which collects satisfaction data directly from consumers. The Outcome and Assessment Information Set (OASIS) documents key aspects of home health care patients' health and functional status. (There are currently no similar data sets for quality in other home and community-based settings or in assisted living facilities.)

All of this information could provide consumers with an invaluable guide to choosing a quality long-term care provider. On the flip side, widespread data dissemination may also give deficient providers the motivation they need to improve their quality scores. A substantial amount of this consumer information is already widely available through the CMS-sponsored "Nursing Home Compare" and "Home Health Compare" Web sites, as well as similar Web sites in a handful of states. Yet, the availability of this quality data has had little impact on occupancy rates, either for high performing or deficient providers.[8] There are several possible reasons for this lack of impact:

- First, efforts to disseminate quality information in a form that consumers can actually understand have been inadequate. A recent study suggests that few consumers are using

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[8] Shugarman, L.R., and Garland, R. 2006. *Nursing Home Selection: How do Consumers Choose? Volume II: Findings from the Website Content Review.* Rand Corporation.

or are even aware of these Web sites.[9] In addition, consumers without Internet access may have trouble accessing data that is only available in electronic form.

- Second, and far more serious, the quality data currently being disseminated for consumer use may not be accurate. In 2002, the House Committee on Government Reform charged that the Nursing Home Compare Web site had major flaws that could mislead families seeking to find a good nursing home. The investigators concluded that Nursing Home Compare "does not include tens of thousands of recent violations of federal health standards, including nearly 60 percent of the violations involving death or serious injury. Many nursing homes with documented violations of federal health standards are incorrectly portrayed on 'Nursing Home Compare' as complying with federal standards."[10]

The Role of Providers

Providers in all segments of the long-term care field have a critical role to play in the transformation of long-term care — by transforming their own long-term care settings and by working with other providers to ensure that they understand the concept of transformation and the steps necessary to achieve it.

Providers are currently participating in voluntary programs to improve care and institute new practices at the facility and agency level. One notable example is Quality First, a program sponsored by the Alliance for Quality Long-Term Care, the American Association of Homes and Services for the Aging and the American Health Care Association. Quality First offers technical assistance and resources to help providers systematically study the care and services they provide, and then engage staff, board members, consumers and other stakeholders in an effort to make improvements. Expanding these voluntary efforts and encouraging more providers to participate in them could be an important element of a multipronged effort to

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[9] Stevenson, D.G. 2006. "Is a Public Reporting Approach Appropriate for Nursing Home Care?" *Journal of Health Politics, Policy and Law*, 31(4), 773-810.

[10] Minority Staff, Special Investigations Division, Committee on Government Reform, U.S. House of Representatives. 2002. *HHS "Nursing Home Compare" Website Has Major Flaws.* Report prepared for Rep. Henry A. Waxman and Sen. Charles E. Grassley, February 21.

improve quality in long-term care. However, voluntary efforts are only one way to address quality. Providers also have a responsibility to meet existing statutory and regulatory quality standards; doing so is another critical way to help ensure quality.

Family Caregivers

Recent studies have attempted to estimate just how many hours family and friends devote to the care of older, frail adults. The exact estimates vary, depending on the source, but they are always substantial. A recent AARP study quantified informal care by estimating that family caregivers provided $350 billion worth of care in 2006. This dollar figure translates into roughly 34 million informal caregivers providing an average of 21 hours of care per week to adults with limitations in their ability to perform routine daily activities such as dressing and toileting, according to the AARP report.[11]

The contributions of family caregivers cannot be ignored or underestimated. Without these daughters, spouses, sons, siblings, neighbors and friends, the nation would never be able to care adequately for its frail older adults — especially with the level of care and concern that close relatives and friends often provide.

Informal care comes with its own costs, however. Working caregivers who go from full-time to part-time status or leave a job to perform caregiving responsibilities experience an average lifetime total wealth loss of $659,139, according to the Metlife Mature Market Institute.[12] This figure includes lost wages, Social Security and pension benefits. In addition, many caregivers are forced to shoulder the cost of care and services. Caregivers who live daily with the mental and emotional stress and the physical challenges of caring for relatives with complex and persistent needs often face physical and mental health risks.

The needs of caregivers have received more attention from policy makers in recent years, particularly with the passage in 2000 of the National Family Caregiver Support Program,

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[11] AARP. 2007. *Valuing the Invaluable: A New Look at the Economic Value of Family Caregiving.* Washington, DC: AARP.

[12] MetLife Mature Market Institute. 1999. *The MetLife Juggling Act Study – Balancing Caregiving with Work and the Costs Involved.* New York: Metropolitan Life Insurance Company.

through which AoA helps states, local communities and tribal organizations provide a continuum of caregiver services. While the program has successfully assisted millions of caregivers — far exceeding AoA expectations — it has addressed only a fraction of the need. Additional legislation to support caregivers has been considered over the past few years, including the Lifespan Respite Care Act, signed into law in December 2006, which created a yet-unfunded program to help states offer caregivers needed and periodic breaks ("respite") from their caregiving responsibilities. These programs represent important, albeit small, steps to reach out to caregivers in a meaningful way that assesses and addresses their needs for support before they or the people in their care experience any adverse effects.[13] However, additional steps are needed to adequately support the family caregivers who still provide the bulk of long-term care in this country.

End-of-Life Care

It has been said that the truest test of any society is the way it treats its most vulnerable members. In much the same way, the true test of a long-term care setting — that is, whether that setting is truly person-centered — is how it treats older people at their most vulnerable stage, as they face the end of their lives. Consumer-centered, end-of life care will incorporate several elements, outlined by the Center for Gerontology and Health Care Research at the Brown University School of Medicine:[14]

- The dying person's physical and emotional discomfort is recognized and he/she receives his/her desired level of comfort.

- Health care providers communicate and negotiate with the person regarding goals of care and formulate plans, including contingency plans, so that the person's preferences are honored.

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[13] AARP. 2006. *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support.* Washington, DC: AARP.

[14] Teno, J.M., Okun, S.N., Casey, V., and Rochon, T. 2001. *Toolkit of Instruments to Measure End of Life Care (TIME) Resource Guide: Achieving Quality of Care at Life's End* Available at: http://www.chcr.brown.edu/pcoc/toolkit.htm.

- The person and his/her family are informed about the person's illness, its disease trajectory and prognosis. Medical decisions should reflect the person's desired involvement and informed preferences.

- The dying person is treated with respect and dignity. This includes helping the person achieve his/her desired level of control over functioning and daily activities.

- The dying person and family are able to achieve desired closure in personal relationships and transcendence.

- The family receives the desired support prior to and after the person's death, including appropriate referral for bereavement services.

- Family caregivers have confidence in their ability to help the dying person in management of his/her medical care.

Death is not a subject that all long-term care providers are able to discuss openly with the people they serve. As a result, not all long-term care providers do a satisfactory job of easing the journey from life to death either for the 67 percent of older people who die in institutions or the third (32.9%) who die at home.[15] Excellent practice guidelines for such services exist, including the Clinical Practice Guidelines for Quality Palliative Care published by the National Consensus Project for Palliative Care in Brooklyn, N.Y. Such practices have not been adopted widely.

The reasons for long-term care's failure to address issues of death and dying are varied and have their roots in society's general aversion to death, as well as regulatory and legal concerns that may lead long-term care facilities to pursue unnecessary interventions at the

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[15] Teno, J.M., Clarridge, B.R., Casey, V., Welch, L., Wetle, T., Shield, R. 2004. "Family Perspectives on End-of-Life Care at the Last Place of Care," *JAMA* 291:88-93.

end of life to avoid accusations of patient neglect. In addition, long-term care providers may not spend enough time working with patients to develop clear advanced directives so that all caregivers truly understand the wishes of the dying person. Financial issues may also affect the availability of palliative care. For example, *The New York Times* reports that consumers aren't choosing hospice in greater numbers because many insurance programs — including Medicare — will only pay for hospice care if the patient gives up all life-prolonging medical treatment and any hope of recovery.[16] These insurance restrictions have, essentially, taken away from older persons the most important choice of their lives — the choice about how they will die. A better, "open access" approach, which is currently available through a handful of private insurance providers, would improve older patients' quality of life by allowing them to benefit from hospice care and, at the same time, continue making their own decisions about ongoing medical treatment.

Long-term care providers have an important role to play in helping many older residents approach death. By developing a philosophy of a "good death," by communicating that philosophy to staff and residents and by establishing programs that support that philosophy, these providers can allow residents to die with dignity. Adopting such an approach to end-of-life care may very well be the most valuable gift that long-term care providers can offer to the people they serve.

Next Steps

Older consumers with disabilities seek out long-term care because they are in need of intensely personal services that include help with such basic activities as bathing, dressing and using the bathroom. Meeting those needs with high-quality care requires a deeply personal response to each consumer. As noted here, some progress has been made in the quest to ensure quality in the long-term care environment. But, as the following recommendations illustrate, much remains to be done.

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[16] Abelson, Reed. 2007. "A Chance to Pick Hospice, and Still Hope to Live," *The New York Times*, February 10, 2007.

QUALITY RECOMMENDATIONS

I. OBJECTIVES/PRINCIPLES

1. Quality in long-term care refers to the quality of long-term care *settings*, such as adult day care or assisted living, and to the quality of long-term care *processes*, such as transitions between care settings or end-of-life care. Quality in long-term care should be assessed according to the six elements of quality identified by the Institute of Medicine in its *Cross the Quality Chasm* report.[17] Accordingly, care will be:

   o Safe.

   o Effective.

   o Efficient.

   o Timely.

   o Person-centered.

   o Equitable.

2. A critical part of long-term care quality is the individual's quality of life. Giving individuals more choice and control over the services they receive in the settings of their choice will enhance their quality of life. Consumers and their caregivers are usually the ones who can best evaluate the personal control they have over services and support.

3. Most people with functional disabilities receive services in their own homes, generally from unpaid caregivers. Offering support to caregivers should be a critical component of any plan to improve the quality of services provided to persons with disabilities in their homes. More emphasis and resources should be placed on monitoring the quality of agency-provided services in the home.

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[17] Institute of Medicine. 2000. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academy Press.

4. The cornerstones of culture transformation in long-term care are: (1) person-centered care; (2) a physical environment that is residential and home-like; and (3) the empowerment of the caregivers who work most closely with older consumers. Long-term care consumers, including those living in both institutional and non-institutional settings, must be allowed to make choices in meaningful ways, as should their direct caregivers.

II. QUALITY MEASUREMENT AND DATA

5. A common set of measures for quality of long-term care should be developed that is standardized, comprehensive and clear. Systems should be designed to identify gradations of quality. In addition, it is important that excellence be recognized at the same time that poor performance is identified and corrected. Core measures of quality should cover both quality of care and quality of life and should be common across all long-term care settings so that outcomes can be compared across settings.

6. Quality measures should be designed to minimize the burden associated with collecting the data. Since many measures will likely involve self-reporting by providers, data need to be easily verifiable.

7. Individual and family satisfaction and experience with care are critical dimensions of quality. Satisfaction should be uniformly measured and reported consistently across all settings and services in a way that meets consumer needs.

8. Collection of quality measures must be sufficient to provide adequate and current assessments of all services and providers. Inadequacies in existing data collection need to be remedied. For example, while 80 percent of Medicare skilled nursing facility residents receive physical therapy, assessment of outcomes is not possible since assessment data are not collected and reported at discharge.

9. Measures need to be kept current. Review of the need for revisions should occur frequently (perhaps every two-to-three years) as new research findings become available to inform the process. Federal support for research needed to maintain current and relevant measures is essential.

10. Composite measures that summarize and weigh the many individual measures should be created to allow overall assessment of providers' quality and offer clear and consistent information about relative performance of different providers. Such an easy-to-understand scoring system should be developed in conjunction with consumer groups, provider groups, governmental agencies and other interested parties.

11. In the short term, better use of the Long-Term Care Minimum Data Set (MDS) should be made. MDS data should be evaluated to determine which data are appropriate to use for which purposes and which data might need to be improved before they can be used for additional purposes.

III. INFORMING CONSUMERS

12. Substantial investments should be made in the dissemination of comparative quality information to consumers as a way to promote quality improvements through competition. The development of quality measures discussed above needs to produce clear, comprehensive and valid information readily usable by consumers in varying circumstances. Dissemination should involve active outreach to consumers through state and local health departments, the Aging Network that includes State and Area Agencies on Aging, single points of entry, consumer councils and other community-based outlets where consumers are likely to seek information about long-term care.

13. Dissemination efforts should build upon and improve current information outlets, such as the Nursing Home Compare and Home Health Compare Web sites. These outlets should include quality reports on a broader range of facilities and agencies (including private nursing homes, State Veterans Homes, Veterans Health Administration nursing

homes and assisted living facilities) and should employ broad-based outreach methods, in addition to the Internet, to promote the widest possible awareness of long-term care quality.

14. Comprehensive survey results should be made available to the public in print and electronic formats that are easy for consumers to understand. This information should include the results of complaint investigations and other information related to quality, such as staffing levels and staff turnover.

IV. OVERSIGHT

15. Standards for certification or licensure are critical and must ensure acceptable performance for services provided in all settings. These standards should be comprehensive and efficient. They should reflect all important quality dimensions, especially person-centered care, within a minimum number of standards. Finally, standards should be clear so that they can be applied consistently.

16. Standards and inspections should be transformed so that they no longer focus only on the detection of deficiencies, but also assess relative performance and identify excellence. Poor and unacceptable performance should still be identified, scrutinized and effectively addressed. Appropriate due process procedures need to be in place for resolution of disputed survey findings. Providers' performance scores should be publicly available. Summary measures of performance with respect to certification and licensure standards should be developed.

17. Sufficient resources need to be invested to assure thorough and consistent oversight. It is necessary to train an adequate number of surveyors and provide sufficient oversight of and support of their work. Alternative methods of timing for surveys should be explored so that surveys will be less predictable. For example, surveys could be triggered by complaints, by changes in top leadership at the long-term care setting or by random selection using a table of random numbers; they could also occur at different times of

day and night and on weekends. State-to-state consistencies could be examined by CMS, which should develop tools to benchmark results of the survey process.

18. There should be a national effort to close chronically poor performing long-term care facilities. This effort should involve federal and state agencies, elected officials, the private sector, consumers, organized labor and professional groups. Obstacles to the closing of poor performers should be removed and an array of effective enforcement techniques should be developed and deployed to achieve this goal.

V. HOME CARE AND FAMILY CAREGIVERS

19. To enable family caregivers to help individuals with disabilities live in their homes, adequate supports should be available, including: assessments of caregivers' needs, voluntary training and respite for family caregivers, home assessments for accessibility, technical help from health care professionals, a reliable back-up system of direct care workers and help-lines through which health care professionals can provide technical assistance. Many of these are already provisions within the under-funded National Family Caregiver Support Program.

20. Additional resources and training should be allocated for monitoring and enforcement efforts related to agency-provided long-term care services in the home.

VI. TECHNICAL ASSISTANCE

21. Technical assistance should be available to providers to facilitate improvements in quality of their care and their compliance with quality standards. Quality Improvement Organizations may be one entity to provide such assistance. Other entities should be identified to help carry out this recommendation, since long-term care involves a multiplicity of provider types and an array of non-medical services.

22. Technical assistance efforts must be clearly separated from monitoring and enforcements functions.

VII. END-OF-LIFE CARE

23. Long-term care providers have a special obligation to identify and address the physical, palliative, psychosocial and spiritual needs of individuals who are in the final phases of life, especially individuals who are using residential long-term care services.

24. Increased flexibility is needed when defining eligibility for hospice, provided at home or in the nursing home, and palliative care services under the Medicare program. Policy makers should consider how Medicare can best be structured to support those with terminal illnesses through the provision of palliative care and hospice services.

25. Because movement between settings is typical of those requiring long-term care, mechanisms or processes must be developed that keep individuals' vital clinical information with them as they move between care settings. These mechanisms and processes must be designed in a manner that protects the privacy and security of consumer information.

26. Steps should be taken to: (1) help long-term care consumers avoid preventable hospitalizations when possible; (2) improve those transitions to acute care when they are necessary; and (3) involve individuals and family caregivers in all phases of care transitions.

CHAPTER 2: WORKFORCE[18]

In a 2002 commentary that he wrote for the *North Carolina Medical Journal*, Dr. Thomas R. Konrad, a professor at the University of North Carolina School of Medicine, suggested that health care policy makers need to apply the "mom test" to any decisions or pronouncements about the long-term care workforce. This test, recommended to Konrad by the late John Eisenberg, MD, who headed the federal Agency for Healthcare Research and Quality, asks a simple question: "What kind of a person do we want to be taking care of our own mom?" If stakeholders can come to a consensus on the answer to that question, suggested Konrad in his commentary, "we will be on our way."[19]

How would each of us answer Konrad and Eisenberg's question? Common sense suggests that we might envision a paid caregiver who is happy and fulfilled in his or her work; one who understands the special needs of an aging population and how those needs change with time; one who is trained to provide quality care; and one who plans to stay on the job long enough to develop a long-term, caring relationship with our mothers. If truth be told, however, we as a nation are not quite "on our way" to ensuring that these types of people will be caring for our mothers in the decades to come.

At the most basic level, the nation may end up failing our mothers simply because we won't have adequate numbers of trained professionals available to help them when they begin to need assistance with the activities of daily living. There is already a well-documented shortage of competent workers who can manage, supervise and provide long-term care services in facilities and private homes throughout the country. As a result, our mothers are

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[18] Unless otherwise noted, the information contained in this overview is taken from *The Long-Term Care Workforce: Can the Crisis be Fixed?,* presented to the Commission in January 2007 by the Institute for the Future of Aging Services. Examples of workforce initiatives are taken from "Better Jobs Better Care: Building a Valued, Committed Workforce," *FutureAge*, Volume 6, No. 2, March/April 2007.

[19] Konrad, Thomas R. 2002. "Who Do We Want to Care for our Mothers? Redefining and Reinforcing the Direct Care Workforce." *North Carolina Medical Journal*, March/April 2002, Volume 63 Number 2.

already having problems accessing services and, in some cases, their safety, quality of care and quality of life are being compromised in the process. Unfortunately, the problem will only get worse unless effective steps are taken to develop the workforce needed to meet future demand for services.

Direct Care Workers

Direct care workers — the paraprofessionals who help older people carry out the basic activities of daily living — are both at the heart of the long-term care workforce and at the heart of its labor shortage. The harsh reality is that this workforce is in danger of buckling under the pressure of simple arithmetic. A report presented to the Commission by the Institute for the Future of Aging Services (IFAS) suggests that between now and 2015, the population aged 85 years and older — the age at which most people begin to require long-term care — will increase by 40 percent. However, the native-born population aged 24 to 54 — the age of most paid and informal caregivers — will not increase at all.

One doesn't need a calculator to realize that, in less than a decade, the pool of available long-term care professionals and direct care workers will be much smaller than needed. And the need for more and better qualified caregivers will become even more critical as the years pass. Even if we set the somewhat conservative goal to maintain the current ratio of paid long-term care workers to the current population of 85-year-olds, the long-term care workforce would have to grow by two percent a year — to the tune of 4 million new workers — by 2050.[20] To make matters worse, family caregivers, who now care for three-quarters of adults with disabilities, can't be counted on to fill the care gap as they do now. When Baby Boomers turn 85, they will not have as many children to care for them as do today's 85-year-olds.

Clearly, the demographics of the future aging population will present long-term care recruiters with a huge challenge for many years to come. But demographics are not the only

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[20] Friedland, L., Newman S., Gray, L., and Kolb, K. 2004. *The State of the States in Family Caregiving Support: A 50 State Study*. San Francisco, California: Family Caregiver Alliance, National Center on Caregiving.

challenge facing those whose job it will be to find qualified individuals to work in long-term care settings. The negative attitudes about aging and long-term care held by many prospective workers will make recruitment difficult, even for providers that have earned a reputation for quality. Throw in a job description that features a heavy workload, insufficient pay and inadequate benefits, and the job of recruiting and retaining direct care workers may become virtually impossible. Even today, turnover rates among these workers can be over 75 percent.

In addition to putting quality of care in jeopardy, these recruitment issues also place burdens on those already working in long-term care, including administrators, supervisors and direct care workers. Long-term care administrators and supervisors, forced to manage an unstable labor pool while trying to serve a growing aging population, will find the cost of care rise dramatically as they continually recruit and train new employees or hire temporary workers with higher pay. Individuals who answer the call to work in long-term care settings will find themselves working harder, doing more varied tasks during the course of a workday and, as a result, putting themselves at greater risk for accident and injury.

Long-Term Care Professionals

Recruitment and retention issues aren't limited to direct care workers; they also affect the professionals who work in long-term care settings, including medical directors, administrators, licensed nurses and academically trained social workers. Currently, there are an insufficient number of these professionals providing care and services to older persons and their families, and projections for the future are not sanguine:

- In medical schools, students remain reluctant to elect work with older persons, only to discover — years later when they are internists unschooled in the subtleties of work with older patients — that their clientele are most often older.

- In social work, approximately one-third of currently practicing professionals in all fields (not just aging) is slated to retire within a matter of years. This development could result

in an enormous staffing shortfall in community-based adult day care, respite, specialized Alzheimer's, case management and other programs that fill a wide range of consumer and caregiver needs.

- While the nursing profession has aggressively sought to attract students to its educational programs, it now finds itself in the position of turning away qualified applicants, according the American Association of Colleges of Nursing (AACN). A 2004 AACN survey determined that 32,797 qualified applications to baccalaureate, master's, and doctoral nursing programs were not accepted; an insufficient number of faculty was cited by 47.8 percent of responding schools as the major reason for not accepting all qualified applicants.[21]

For a number of years, the John A. Hartford Foundation and other philanthropic organizations have attempted to bolster the number of geriatricians, geriatric nurses and geriatric social workers by supporting the development of faculty scholars in schools of medicine, nursing and social work. These scholars have two goals: to teach aging-related courses and to attract students into each of these professions. This is an important initiative and similar initiatives should be encouraged.

Improving and maintaining quality in long-term care will also require that nursing home, assisted living and community-based service providers ask important questions about the role that professionals can and should play in long-term care. Providers need to find ways to attract more of these professionals to the long-term care field. In addition, providers must ensure that these professionals are properly trained and educated, and that long-term care settings take full advantage of the expertise and experience that professionals have to offer.

Take physicians, for example. Since 1990, nursing homes reimbursed by Medicare or Medicaid have been required to employ a physician medical director who is responsible for implementing medical care policies and coordinating medical care. Nursing homes have met

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[21] American Association of Colleges of Nursing. 2005. *Faculty Shortages in Baccalaureate and Graduate Nursing Programs: Scope of the Problem and Strategies for Expanding the Supply.* Washington, DC: AACN. Available at: http://www.aacn.nche.edu/Publications/pdf/05FacShortage.pdf.

the "letter of the law" regarding this requirement over the past two decades, but they have a long way to go before they fulfill the *intent* of the requirement — that is, to enhance the medical services available to long-term care consumers. The reality is that few medical directors are adequately prepared for their long-term care jobs and few are very actively involved in long-term care settings. Physician involvement with older people receiving home and community-based services has also been marred by lack of coordination and communication. Clearly, long-term care providers could make better use of the expertise that medical directors have to offer while, at the same time, taking care not to over-medicalize long-term care settings.

Nurse practitioners (NP) could help fill the medical-services gap in long-term care. However, while Medicare has reimbursed their services since 1998, it remains unclear just how many NPs are currently involved in long-term care. What we *do* know is that NPs working in nursing homes have enhanced the medical services provided there, prevented unnecessary hospital admissions and helped residents and family members feel more satisfied with long-term care services. It seems clear that long-term care settings could benefit from the involvement of more NPs.

Quality outcomes are also tied to the training and job satisfaction of two other types of long-term care professionals: (1) administrators, who oversee the day-to-day operations of a variety of long-term care settings and (2) nurses, whose challenging jobs combine administrative and supervisory duties with responsibilities for assessing resident health and developing treatment plans. High turnover among administrators, in addition to declines in the number of new administrators entering the field, has caused concerns about long-term care quality in recent years, especially in light of studies that have linked administrator turnover with poor quality outcomes among nursing home residents.[22] Studies have also linked high turnover among registered nurses (RNs) with poor quality outcomes in long-term care settings. With RN turnover rates holding at 49 percent — and studies showing

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[22] Castle, N.G. 2001. "Administrator Turnover and Quality of Care in Nursing Homes." *The Gerontologist*, 41, 757-767. Cited in Institute for the Future of Aging Services (IFAS). 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?* Washington, DC: AAHSA and IFAS.

that RNs have the lowest job satisfaction of all professionals[23] — the implications for quality will be alarming unless positive action is taken to increase job satisfaction among these important long-term care professionals. As mentioned in the previous section, and as noted on Table 1, turnover rates are even higher among direct care staff. This turnover also affects quality.

Workforce Issues

Solving the long-term care workforce crisis won't be easy or simple. It will require innovative strategies and decisive action to improve many aspects of the long-term care work environment, including improvements to training, compensation, job safety and working conditions. It will involve educating prospective employees about the aging process and the evolving face of long-term care. And, it will require a significant effort to answer big questions about how long-term care should be designed, delivered and financed to meet the future demand for its services. The answers to these big questions will have a significant impact on workforce issues because those answers will determine how many people will be needed in the long-term care workforce; how they will be recruited, compensated and trained; what duties they will perform; and in which settings they will work. Other issues, including the use of technology in long-term care settings and the degree to which long-term care providers will adopt consumer-directed care approaches, will also have a tremendous impact on what long-term care workers do and how they interact with consumers.

We don't yet know the answers to many of these questions. Yet, despite these unknowns, we can be sure that certain core workforce issues won't go away or solve themselves in the coming decades. Even a cursory glance at Table 1 (page 53), which presents a profile of the long-term care workforce, underscores the importance of three issue areas, which the Commission believes are at the heart of the workforce crisis and require the nation's

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[23] Spratley, E., Johnson, A., Sochalski, J., Fritz, M., and Spencer, W. 2001. *The Registered Nurse Population, March 2000: Findings from the National Sample Survey of Registered Nurses.* Rockville, MD: U.S. Department of Health and Human Services, Bureau of Health Professions. Cited in Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?* Washington, DC: AAHSA and IFAS.

immediate attention: compensation and benefits, preparation and training, and working conditions.

Compensation and Benefits

It doesn't take an economist to figure out the basic economic reality that long-term care providers face every day. When the economy is strong, and unemployment is low, job seekers have more options regarding the type of job they will take and the compensation they will accept. So the best strategy to attract workers is to offer competitive compensation packages that include good pay and valuable benefits. This reality applies to physicians, nurses and administrators who work in long-term care and typically are compensated at rates below the average acute-care health professional. But it is particularly true for direct care workers. In return for taking care of the most basic and intimate needs of older individuals with disabilities, these workers earn about as much as the cashier at your local fast food restaurant. In addition, they are less likely than other long-term care workers to have health insurance and more likely to work part-time. It's no surprise that nearly a third of them live at or below the poverty line.

Wage and benefit increases have been shown to help in the recruitment and retention of this workforce. For example, when San Francisco County doubled the wages of its In-Home Supportive Services (IHSS) personnel, the number of those workers increased by 54 percent. The turnover rate among IHSS workers was 70 percent when those workers were paid close to minimum wage. That turnover rate dropped to 35 percent after workers started getting $10 an hour and gaining access to health and dental benefits.

On the other side of the country, the Vermont Department of Disabilities, Aging and Independent Living is hoping its own actions to raise wages for workers in the state's Medicaid waiver program will have similar results and will help set a standard that forces other providers to change their own compensation policies. Elsewhere in the nation, additional strategies are being proposed that would use Medicaid funds to improve compensation packages for long-term care workers. One strategy calls for increasing Medicaid reimbursement to long-term care providers with the expectation that such

increases will be directly passed through to frontline workers in the form of higher wages or benefits. According to IFAS, research evaluating the impact of these wage "pass-throughs" has been mixed, and experts are suggesting that better accountability mechanisms are needed to ensure that the earmarked funds actually make it into workers' paychecks.

Inadequate Preparation and Training

As noted earlier, many individuals working in long-term care — including physicians, nurses, administrators and direct care workers — could play a greater role in providing quality care if they were better prepared for their jobs. For example, physicians and nurse practitioners, who bring valuable medical services and expertise to long-term care settings, would benefit from more training in geriatrics. The same is true for administrators and registered nurses, who perform the majority of administrative duties within long-term care settings. The federal government requires states to license nursing home administrators. However, it also allows those states to decide for themselves whether and how to credential other long-term care administrators, including those that oversee the operations of assisted living facilities and home health agencies. RNs receive several years of education, but their training often includes little information about long-term care and little training in the specific skills they need to carry out their growing supervisory duties.

Of greatest concern is the fact that most states require little or no training for direct care workers, the frontline workers who provide the bulk of hands-on care in long-term care settings. While all states require training for Certified Nursing Assistants (CNAs) who work in nursing homes, training requirements are generally lower for direct care staff working in assisted living facilities. Paid caregivers who work independently for individual consumers frequently have little-to-no formal training. As a result, many of these caregivers often feel unprepared for the jobs they are asked to do, and overwhelmed enough to leave those jobs within the first few months.

Table 1: Profile of the Long-Term Care (LTC) Workforce

Staff Person	Duties	Level of Training	Full-Time Salary[24] (National Average)	Issues
Nursing Home Administrators	Responsible for all facets of facility life, including the supervision and management of staff and compliance with federal and state regulations.	Federal government requires states to license administrators, but there are no national standards. Most states require candidates to pass an exam and complete an unpaid apprenticeship.	$79,454[25]	There have been recent sharp declines in new administrators and high rates of turnover (43%) among current job holders.[26]
Registered Nurses (RN)	Hold administrative and supervisory positions in nursing homes and home health agencies.	Licensed by the state after 2-4 years of nursing education, which may not include training in geriatrics or supervisory skills.	• $54,550 in home health agencies. • $51,510 in nursing homes. • (RNs in hospitals earn $57,820).	• High turnover (49%) and vacancy rates (18.4%).[27] • RNs have a positive impact on quality outcomes for nursing home residents. • Job satisfaction is low.
Licensed Practical Nurses (LPN)	Provide direct patient care, including medication management. Supervise care provided by direct care workers.	Licensed by state after 12-18 months of education.	• $37,810 in home health agencies. • $37, 520 in nursing homes.	• High turnover (50%) and vacancy rates (14.4%).
Direct Care Workers	Help frail and older individuals with disabilities carry out activities of daily living.	Federal law requires less than two weeks of training, but most states add on to these requirements.	• $17,710 for personal and home care aides. • $18,850 for home health aides. • $21,480 for nurse's aides and orderlies in nursing homes. • Wages are comparable to salaries earned by maids, housekeepers and fast-food workers.	• One in four lacks health insurance. • 30 percent live at or below the poverty level.[28] • High turnover (76%) and vacancy (12%) rates.

[24] Bureau of Labor Statistics. 2006. *Occupational Outlook Handbook, 2006-07 Edition.* Retrieved from http://www.bls.gov/oco/home.htm. Cited in Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?* Washington, DC: AAHSA and IFAS.

[25] Hospital & Healthcare Compensation Service. 2005. *AAHSA Nursing Home Salary & Benefits Report 2005-2006.* Oakland, New Jersey.

[26] Castle, N.G. 2001. "Administrator Turnover and Quality of Care in Nursing Homes." *The Gerontologist*, 41, 757-767. Cited in Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?*

[27] All turnover and vacancy rates come from American Health Care Association. 2003. *Results of the 2002 AHCA Survey of Nursing Staff Vacancy and Turnover in Nursing Homes.* Washington, DC: author. Cited in Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?*

[28] Salsberg, E. 2003. *Making Sense of the System: How States Can Use Health Workforce Policies to Increase Access and Improve Quality of Care.* New York, NY: Milbank Memorial Fund. Cited in Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?*

Adequately training workers is not without its challenges. States and individual providers struggle with ways to encourage direct care staff to enroll in and stick with training programs when those workers may be inexperienced and uncomfortable with classroom learning, and when family and work responsibilities keep them from attending class. An inventive program in North Carolina seems to overcome these barriers by bringing a 33-hour curriculum to direct care workers in the state's nursing homes as a way to improve their clinical and interpersonal skills. The key to the success of WIN A STEP UP is that classes are offered on site during the regular workday and are tailored to individuals' education levels and learning styles. To encourage participation, those who successfully complete the program receive a pay raise or bonus in return for a commitment to stay in their jobs for at least three months. Evaluations of the program conducted by the University of North Carolina found that the on-site training initiative has made workers more confident in their jobs, increased their job satisfaction, added to their knowledge and improved their ability to work in teams.

At the federal level, the President's High Growth Job Training Initiative, administered by the Employment and Training Administration in the U.S. Department of Labor, has targeted $3 million dollars to encourage regional approaches to meeting long-term care workforce challenges. Through the grant program, six organizations have received $500,000 each to prepare workers for careers in long-term care. Grant-supported initiatives are creating CNA career tracks, delivering on-the-job talent development programs and developing credential and certification programs to prepare community college students to advance up the nursing career ladder. The High Growth initiative is a good example of what can be accomplished when public- and private-sector partners come together to implement education programs. These and similar programs promise to help create a pipeline of qualified workers to meet the needs of the future long-term care consumer.

Working Conditions

Long-term care workers have typically characterized their work settings as being organized in a hierarchal way and marred by a culture that doesn't provide adequate supervision, doesn't respect the knowledge and skills that nurses and aides bring to their work and doesn't

encourage information sharing among employees at different levels of the organization. Given this history, it will take deliberate efforts and hard work to transform long-term care settings into places where people want to work — and continue working. But recent efforts in various areas show that such transformation efforts can be effective. Some examples follow:

Retention efforts. The experience of Better Jobs Better Care (BJBC), a four-year, $15.5 million research and demonstration program funded by the Robert Wood Johnson Foundation and The Atlantic Philanthropies, suggests that progress can be made in building a high-quality long-term care workforce through a comprehensive effort to change the culture of the long-term care workplace. BJBC grantees provide myriad examples of the type of workforce changes that can be realized when care settings place a priority on staff retention and advancement. For example, by training and supporting "retention specialists" at several nursing facilities in New York and Connecticut, and providing them with evidence-based models to address problems of job satisfaction, Cornell University's Institute for Translational Research on Aging was able to lower average staff turnover from 21 percent to 11 percent over one year. Strategies utilized in the BJBC-funded initiative included peer mentoring programs through which experienced aides provided on-the-job support and guidance to other aides. In addition, career-advancement initiatives offered flexible schedules and encouragement to aides interested in attending nursing school.

Worker associations. Some states have found that they can build the confidence and commitment of long-term care workers by encouraging them to form associations through which they can support one another and advocate for better work environments. In Vermont, for example, the State Department of Disabilities, Aging and Independent Living (DAIL) earmarked funding in Medicaid's "Real Choices" waiver to create the Vermont Association of Professional Care Providers, the state's first professional association for direct care workers. The association now provides ongoing training for its members and meets quarterly with the DAIL commissioner to discuss worker needs and concerns. Similar associations around the country have developed their own initiatives to improve the long-term care workforce, and have given long-term care workers a personal stake in their futures.

Provider coalitions. A coalition of Wisconsin providers was responsible for developing the revolutionary Wellspring model, which has been replicated in several states. Wellspring was developed by an alliance of 11 freestanding, not-for-profit nursing homes that came together in 1998 to improve the quality of their care and work environments. In that effort, they have employed such strategies as collaborative training programs, sharing of resident data and the use of multidisciplinary teams to implement care-improvement interventions. A recent evaluation funded by the Commonwealth Fund credited Wellspring with lowering the rate of staff turnover in member facilities, improving the performance of those facilities on federal surveys and helping staff take a more proactive approach to resident care.[29]

Any effort to improve working conditions for long-term care workers must include aggressive action to make the work environment safer. This is a challenging task, since long-term care settings have extremely high accident and injury rates. Alison Trinkoff and her colleagues report in a 2005 paper that the rate of worker injuries within nursing and personal care facilities is second among all industries. Nursing homes place among the top 10 industries for musculoskeletal problems, the major cause of worker absenteeism, workers' compensation claims and worker injury and illness.[30] The very nature of long-term care jobs explains the high injury rates to a certain extent: caring for frail older people literally requires heavy lifting and working in awkward positions. In addition, out-of-date equipment, inefficient job designs and low staffing levels exacerbate the risks of injury that workers encounter on the job each day. These risks and dangers must be addressed before long-term care settings can become places where skilled and caring individuals will want to work — and will be able to work—over the long term.

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[29] Stone, R.I., Reinhard, S., Bowers, B., Zimmerman, D., Phillips, C., Hawes, C., Fielding, J., and Jacobson, N. 2002. *Evaluation of the Wellspring Model for Improving Nursing Home Quality.* New York: The Commonwealth Fund.

[30] Trinkoff, A., Johantgen, M., Muntaner, C., Rong, L. 2005. "Staffing and Worker Injury in Nursing Homes." *Am J Public Health* 95(7):1220-1225.

Taking a Holistic Approach

In order to resolve the long-term care crisis before it reaches epic proportions, providers must address the need for sufficient compensation, adequate training and good working conditions. By taking positive action in each area, long-term care providers will send a simple, yet powerful message to their workers: that those workers are worth a significant investment and that their service to long-term care consumers is a critical — not a dispensable — component of quality care provision. Only those employers that are willing to make a long-term commitment to their workforce can expect an equally long-term commitment from those workers.

The Green House project, which was first established in 2003 by Mississippi Methodist Senior Services, Inc., in Tupelo, Mississippi, has made such an investment in its workforce. Green Houses, which are small, homelike, intentional communities in which eight to 10 nursing home residents live together and receive needed assistance with activities of daily living, have made a name for themselves in recent years as a stellar example of long-term care culture transformation. In addition to transforming the environments in which nursing home residents live, the model has also transformed the work environment for direct care personnel (called "shahbazim," from the Persian word for "royal falcon"[31]). Green Houses invest in their shahbazim by providing:

- ***Good working conditions***. The Green House work environment empowers frontline staff by allowing shahbazim to take more responsibility for care provision as they work on self-managed teams that have rotating coordinator positions. In addition, Green Houses offer staff a safe environment in which to work. All Green Houses are equipped with state-of-the-art lift equipment, which allows staff to transfer residents more easily and with less risk of injury.

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[31] For more information about Green Houses, and the origin of the word Shahbazim, see Thomas, W.H., 2004. *What Are Old People For? How Elders Will Save the World.* Acton, Massachusetts: Vanderwyk & Burnham.

- ***Competitive compensation***. When the first Green Houses opened in 2003, shahbazim were paid $11 an hour, a rate that was $4 more than was paid to CNAs who continued to work in Methodist Senior Services' traditional nursing home units.

- ***Sufficient training***. Shahbazim who are not CNAs when they are hired must undergo training and become state certified. Once hired, they receive 120 hours of additional training: 40 hours with Green House staff to learn about the project's philosophy, policy and procedures; and 80 hours with outside professionals who teach classes on first aid, CPR, culinary skills, food safety and home repairs.

These investments have shown good results, according to an evaluation of the Tupelo Green Houses conducted by Rosalie Kane of the University of Minnesota. Kane's evaluation shows that turnover rates among nursing assistants dropped to nearly zero after the Green House project began and that Green House staff have high levels of job satisfaction.[32] In addition, according to a 2006 article in *The Gerontologist*, transfer-related injuries among staff have dropped dramatically; none were reported during the evaluation period. The article attributed this improvement to higher levels of staff empowerment, which encourages staff members to demonstrate increased skills and self-esteem.[33]

Next Steps

All of these workforce initiatives are encouraging, both because they exist at all and because they are showing positive outcomes in recruiting, training and retaining a qualified long-term care workforce. Now it's time to establish similar initiatives in every long-term care setting. This goal is achievable, but it will require hard work. The Commission believes that the following recommendations will help, in the words of Dr. Konrad, set us forward "on our way."

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[32] National Clearinghouse on the Direct Care Workforce. Green House Project. Accessed at: http://www.directcareclearinghouse.org/practices/r_pp_det.jsp?res_id=187910

[33] Rabig, J., Thomas, W., Kane, R., Cutler, L., and McAlilly, S. 2006. "Radical Redesign of Nursing Homes: Applying the Green House Concept in Tupelo, Miss. *The Gerontologist* 46(4):533–39.

WORKFORCE RECOMMENDATIONS

I. RESPECT FOR THE LONG-TERM CARE WORKFORCE

1. Encourage federal and state education, training and workforce development programs to recognize the long-term care workforce as a critical component of the nation's labor force — separate and distinct from the health care labor market.

   Long-term care is not acute care or health care. The long-term care workforce (paid and unpaid) carries out a unique and critical mission to help individuals function as well as possible and maintain their independence in the face of disability. That mission is changing as services are delivered in a growing array of care settings with more emphasis on consumer control. However, the needs of the long-term care workforce are frequently overshadowed by the needs of the higher profile health care sector.

   Federal and state workforce, education, training and development programs (including the Workforce Investment Act, the High Growth Job Training Initiative, the Nurse Reinvestment Act and programs authorized under the Health Professions Education Partnership Act) should receive additional funds to design and implement initiatives aimed at attracting new individuals into the long-term care field and improving their preparation and performance. A federal-state task force should be appointed to oversee the coordination and implementation of this initiative. Modifications of current statutes will be required.

II. LEADERSHIP DEVELOPMENT

2. Develop and support the implementation of a leadership training initiative to improve the supervisory and leadership skills of long-term care managers.

The leadership training initiative could be organized, sponsored, funded and staffed by the major long-term care provider associations and coalitions representing for-profit and not-for-profit nursing homes, assisted living facilities, home care agencies and home health agencies. The following entities should be involved in developing and implementing the initiative: long-term care employers; representatives of professional associations; state boards of nursing and relevant state boards for other professions; long-term care workers; consumers; education institutions; and experts in geriatrics, adult learning, knowledge transfer and cultural diversity. Philanthropic organizations could be called upon to supplement the initiative's funding and staffing levels; to assist in planning, implementing and evaluating the initiative; and to provide ongoing support for replication and wide-scale diffusion.

III. WAGES AND BENEFITS

3. Develop strategies to raise wages and improve benefits for long-term care professionals and direct care workers.

   A working group made up of the American Association of Homes and Services for the Aging, the American Health Care Association, the Alliance for Quality Nursing Home Care, the National Association of Home Care, the National Governors Association, the National Conference of State Legislatures, long-term care workers, consumers and other national and state groups could be charged with developing proposals to leverage current federal and state long-term care funding streams to improve compensation for long-term care professionals and direct care workers. The work group could address such issues as "pay for performance" proposals tied to wage and benefit enhancements and could develop strategies for improving the effectiveness of "Medicaid wage pass-throughs" in increasing wages and benefits. The working group itself would not require new funding; however proposals to improve wage and benefit packages could require new statutory authority and funding.

IV. COMPETENCIES

4. Request that the Institute of Medicine (IOM) conduct an evidence-based study and make recommendations regarding the set of competencies that should be required of direct care workers, nurses, administrators and medical directors employed by nursing homes, assisted living facilities, home care agencies and home health agencies. The IOM should pay particular attention to changes in the workforce due to changes in long-term care delivery and make recommendations regarding how these competencies should be achieved.

   In addition, the IOM should examine the extent to which current requirements and standards for education, credentialing/licensing and in-service training are evidence-based; how these requirements and standards impact recruitment, retention, job performance and quality of care; and the costs — to providers, job candidates, consumers and federal and state government — of implementing changes to those requirements and standards. This recommendation would require new legislation and additional funding.

V. INCENTIVES

5. Encourage states to adopt systematic reforms that address long-term care workforce shortages, with a special emphasis on workforce shortages in rural areas and other underserved areas. Encourage additional reforms to improve the competencies, performance and working conditions of the entire long-term care workforce.

   A new federal grant program could allow states to experiment with innovative ways to improve the recruitment, preparation, credentialing and on-going training of the long-term care workforce and to improve the organization of work and working conditions in long-term care settings. States that participate in the demonstration program would be required to meet strict benchmarks regarding the quality of resident/client care. Planning for the demonstration should be a cooperative venture between the federal government and the states.

CHAPTER 3: TECHNOLOGY[34]

Transitions are difficult for people at any age, whether those transitions involve a child's move from one school to another or an adult's change of job, geographic locale or marital status. Yet people encounter one of their most difficult and challenging life transitions if their ability to live independently begins to diminish. At that point, older adults and people with disabilities often find themselves straddling two distinct care systems: the health care system, which has treated their illnesses and diseases for many years and the long-term care system, which now assists them with the daily supports they need to manage chronic conditions and disabilities.

Making this transition from health care to long-term care can be a difficult ordeal for older people faced with the harsh reality of declining health and the onset of disability. That transition may also be a dangerous one if an older consumer's acute and long-term care providers don't communicate with one another or share the information they possess about his or her treatments and conditions.

The myriad care choices offered within the long-term care system — coupled with the growing complexity of the health care system — make this lack of communication especially problematic for older people. An older adult could receive long-term care services in a variety of settings during the course of later life, including his or her own home, a supportive housing environment, an assisted living facility and a nursing home. While living in each of these settings, the older person may have an ongoing relationship with his or her primary care physician. In addition, he or she may also interact with a variety of other health professionals, including heart or cancer specialists, ophthalmologists, podiatrists, physical therapists, nurses and nursing assistants, to name only a few. Over the course of time, the

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[34] Unless otherwise noted, the information contained in this overview is taken from *Essential but Not Sufficient: Information Technology in Long-Term Care as an Enabler of Consumer Independence and Quality Improvement*, a paper presented to the Commission in September 2007 by Ross D. Martin, MD, MHA, David Brantley and Darcy Dangler, BearingPoint, Inc.

long-term care consumer will likely undergo a fair number of laboratory tests and screenings, may visit the emergency room occasionally and will probably experience multiple hospital admissions.

All of the health professionals whom the older person encounters will have observed their "patient" or "client;" many professionals will make copious notes or record valuable data that describe the consumer's well-being. Almost every health professional will recommend something for the care recipient, whether it is a medication, an exercise regimen, a diet or an ongoing therapy. Indeed, by the time the average American reaches 75, he or she will have amassed a plethora of medical records, created by a variety of health professionals, which will document everything from ingrown toenails and eye problems to strokes, cancer and diabetes. Unfortunately, even the most meticulously constructed health record could have limited usefulness because, like the health care system itself, that record is likely to be fragmented — that is, scattered across multiple care settings with no user-friendly mechanism for bringing an individual's health information together in a comprehensive and informative package.

The fragmentation of health records may have several serious consequences for the quality of care that long-term care consumers receive. First, fragmentation interferes with the ability of individual consumers to make their own health and long-term care decisions. When a consumer's health information is scattered across many care settings, the consumer, or a surrogate decision maker acting on the consumer's behalf, is forced to make informed decisions based on incomplete information. Consumer direction and autonomy suffer in the process, as do quality of care and quality of life.

Secondly, fragmentation wastes time and money. When each care setting is forced to create it own health record for the long-term care consumer, duplicative laboratory tests and, in extreme cases, even duplicative procedures can result.

Most disconcerting is the possibility that health professionals who attempt to care for the consumer in an information vacuum will commit serious errors because they lack a complete

knowledge of the patient's medical history. Imagine, for example, a scenario in which one health professional on the consumer's loosely organized and scattered "care team" doesn't even know that another team member exists, let alone what the other team member has observed, what tests he has ordered or what medications she has prescribed. Or consider the risks associated with another scenario, in which an assisted living resident is taken to a hospital for emergency surgery, then transferred to a nursing home to recuperate, all before a complete set of his medical records — with data from both the assisted living facility and the hospital — can be assembled and passed along to the medical director, nurses or direct care workers at the nursing facility.

Medical errors caused by faulty or incomplete information are tragic enough when they affect one, isolated individual. Unfortunately, bad outcomes and compromised care may become likely in the future unless health care and long-term care professionals work together to create an integrated, technology-based network that fosters communication and information-sharing across varied settings. To date, little progress has been made in providing such a network to the millions of people who currently use long-term care services. Failure to develop such a network will leave future health and long-term care professionals at a distinct disadvantage when they attempt to provide quality care and services to a growing population of older people who will be managing increasingly numerous and complex conditions and disabilities.

The Promise of Technology

The good news is that computer-based technologies already exist that could allow care providers in long-term care, acute care and home-based settings to efficiently collect, manage and share vital information about their clients' medical histories and care regimens. New technology products are continually being developed and many of these products have the potential to improve the quality of long-term care services and help older people remain independent for longer. Additional innovation must be encouraged through the development and implementation of reliable and sustainable funding models for research and development. In addition, technology firms, government agencies and health and long-

term care providers must step beyond the artificial lines that separate their sectors so that information and expertise can be shared, new technologies developed and existing technologies adapted to long-term care settings, including a person's private home, in a way that preserves the dignity and safeguards the privacy of older consumers.

Electronic Health Records. Electronic Health Records (EHRs) — computerized records of an individual's lifetime health status and health care — are being introduced slowly into hospital and other clinical settings, and even more slowly into long-term care settings. Once established within a computer network, these records could potentially be shared with any number of health care providers who have been approved by the consumer. In addition to reviewing the consumer's medical history, health professionals could also update that history by documenting the care that they have provided and making those updates immediately available to other health professionals on the consumer's multisite care team.

The Veterans Health Administration within the Department of Veterans Affairs (VA) has developed a comprehensive EHR system which, combined with an innovative quality management approach, has contributed to a higher quality of care for those who receive VA health services.[35] The VA's work in health information technology (IT) goes back several decades and is a study in how sophisticated EHR systems can be built one step at a time. The agency first created the Decentralized Hospital Computer Program (DHCP), one of the first automated health information systems to support multiple sites and cover the full range of health care settings. The VA followed this innovation with the Veterans Health Information Systems and Technology Architecture (VistA®), a suite of more than 100 applications that support the VA's day-to-day clinical, financial and administrative functions. Most recently, the VA developed the Computerized Patient Record System (CPRS) to provide a graphical user interface to the information captured in VistA®.

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[35] Asch, S.M., McGlynn, E.A., Hogan, M.M., Hayward, R.A., Skekelle, P., Rubenstein, L., Keesey, J., Adams, J., Kerr, E. 2004. "Comparison of Quality of Care for Patients in the Veterans Health Administration and Patients in a National Sample." *Annals of Internal Medicine* 141(12): 938-945.

VistA® and CPRS have been implemented in about 1,400 VA medical centers and at VA outpatient clinics, long-term care facilities and residential rehabilitation facilities. As of December 2005, VistA® systems contained nearly 779 million progress notes, discharge summaries and reports; 1.54 billion orders; and almost 425 million images. More than 577,000 new clinical documents, 906,000 orders and 608,000 images are added each workday.[36]

More research is needed to determine whether EHRs can actually increase quality or save money in long-term care settings. But a year-long evaluation of a Web-based electronic medical record system known as Achieve Matrix® suggests that EHRs can increase communication among staff within long-term care settings and help those staff members more closely monitor residents' health status. In addition, the system that was evaluated in the study was credited with increasing job satisfaction among nurses in the long-term care setting and reducing hospitalizations among residents.[37]

Hopeful about the benefits that EHRs can bring to all health settings, President George W. Bush issued an executive order in 2004 that called for widespread adoption of electronic health records for most Americans in the next decade. Bush's order even established economic incentives for health care providers that instituted health IT and also called for the appointment of a National Coordinator for Health Information Technology. In a follow-up to the executive order, the U.S. Department of Health and Human Services (HHS) has issued a framework that calls for bringing electronic health records into clinical practice to reduce medical errors and duplicative work. As this work continues, it is critical that technology experts, policy makers and care providers recognize the potential vulnerability of EHRs and take concrete steps to ensure the safety and privacy of the consumer health information they contain. These valuable information tools will not become an integral

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[36] Department of Veterans Affairs, Veterans Health Administration. 2006. "VA Health Information Technology." Available at: http://www1.va.gov/vha_oi/docs/VA_Health_IT.pdf.

[37] Cherry, B., Owen, D. 2004. *Evaluation of a Web-Based Electronic Medical Record and Communication System for Long-Term Care Facility Management.* Unpublished paper supported by Achieve Healthcare Technologies, Mildred and Shirley L. Garrison Geriatric Education and Care Center, Sears-Methodist Retirement System, Texas Department of Aging and Disability Services, and Texas Tech University Health Sciences.

component of any quality care delivery system until and unless consumers are confident that their health information is private and secure.

Personal Health Records. The HHS framework also supports development of another technology-related initiative: a Personal Health Record (PHR) that a consumer could use to manage personal health information and make decisions about his or her own care. Consumers would actually own this health record, a Web-based file that would include the types of information that some health care recipients are probably already collecting in paper form from all of their health care providers. The PHR could also include information from the consumer's Electronic Health Record and such anecdotal information as the consumer's weight, blood pressure, glucose levels or exercise regimen.

PHRs provide particular benefits for long-term care consumers who move from one care setting to another: the records are specially designed to travel with the consumer and to ease his or her transition to new care settings and new sets of providers. In addition, consumers could share the record not only with their health care professionals, but also with loved ones and trusted friends who are often intimately involved in their care. Finally, the PHR would play an important role in reinforcing the person-centered, consumer-directed approach to care that is now being advocated by several of the new long-term care models identified in the Quality section of this report. By placing vital and comprehensive medical information in the hands of consumers, PHRs enhance consumer autonomy and control over quality of care and quality of life. As mentioned earlier, developing appropriate privacy and security protections will be critical to ensuring widespread consumer use of PHRs.

PHR technology is already available and being used by several long-term care providers, including Erikson Retirement Communities, a Maryland-based, multifacility organization that has already helped nearly 18,000 of its residents establish such records. The organization, which operates 19 continuing care retirements communities in 10 states, credits its PHRs with saving lives because they enhance communication between physicians and patients. The organization uses a very specific example to illustrate this claim: in 2004, when the Food and Drug Administration recalled the arthritis drug Vioxx after it had been linked

with heart attacks and cardiovascular damage, physicians treating Erickson residents were able to identify, within 15 minutes, all the residents who were taking the drug and to inform each resident, within hours, to stop taking it.

All consumers, regardless of age or disability, may soon receive broader access to PHRs as large companies like Intel, Wal-Mart and Pitney-Bowes prepare to offer their employees the opportunity to create such records, or as computer giants like Microsoft launch commercial health-information initiatives. In addition, members of America's Health Insurance Plans (AHIP) and the Blue Cross Blue Shield Association (BCBSA) have been working on a set of standards that would help insurers exchange the information contained in their customers' PHRs.

Electronic Prescribing. In 2006, the Institute of Medicine (IOM) reported that at least 1.5 million Americans are sickened, injured or killed each year by medications errors that include doctors writing prescriptions that interact dangerously with a patient's other medications or pharmacists dispensing the incorrect dose of a prescribed drug. In addition to being dangerous, these errors can be costly: the IOM estimates that the nation spends about $3.5 billion a year treating the health consequences of medications errors.[38]

Among the most dramatic findings of the IOM report was its estimates that about a quarter of adverse drug events (ADEs) — 800,000 ADEs each year in long-term care facilities and 530,000 ADEs each year among Medicare outpatients — could be prevented through the implementation of electronic prescribing (e-prescribing) systems, among other strategies.[39] Physicians using e-prescribing systems can send a prescription to a pharmacy using an automated data entry system like a desktop or hand-held computer. E-prescribing eliminates medication errors caused by illegible prescriptions. In addition, e-prescribing systems that are compatible with EHR systems allow doctors to check a patient's health record and

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[38] Institute of Medicine of the National Academies. 2006. *Preventing Medication Errors.* Washington, D.C.: The National Academies Press.

[39] Kaufman, M. 2006. "Medication Errors Harming Millions, Report Says." *The Washington Post,* July 21.

medication history before writing a new prescription. This critical step in the prescribing process could help patients avoid potentially harmful drug interactions.

All 50 states now allow physicians to "write" e-prescriptions. Next, health care providers, insurance companies and government agencies must take steps to ensure that physicians and their pharmacies can actually make use of this technology. E-prescribing software and hardware must be developed that are user-friendly and compatible with health IT networks across care settings; these tools must be made widely available to physicians and pharmacies; and standards must be developed to ensure the secure electronic transmission of prescription and patient medical histories between prescribers and pharmacies.

Pubic-private partnerships in many states are beginning to make progress toward meeting at least some of these e-prescribing goals. For example, every physician in New Hampshire will soon receive free access to e-prescribing software, a free pocket computer and a discounted wireless telecommunication plan through a new program launched by Anthem Blue Cross and Blue Shield and the New Hampshire Citizens Health Initiative. Physicians using the system will be able to e-prescribe medication for every patient, even those who are not Anthem members. They will also be able to check the medication history of each patient through a built-in EHR system.

Progress toward e-prescribing is also being made at the federal level. In addition to creating the Medicare prescription drug benefit ("Medicare Part D"), the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 has helped to advance the implementation of electronic prescribing in long-term care settings by mandating the progressive development and adoption of e-prescribing standards. This process must continue so that Medicare beneficiaries can benefit from this promising new technology.

Telemedicine. Collecting, evaluating and sharing "real-time" information about long-term care consumers is one of the goals of telemedicine, an emerging set of technologies that promises to make it easier for older people to remain independent, often in their own homes, while receiving the care and services they need. Taking advantage of computer

technology, the Internet and telephone lines, these technologies can be used to transmit a variety of data — including information about a long-term care consumer's vital signs, medication compliance and mental acuity — to a doctor's office or to a relative's computer at any time of the day or night. In addition, so-called "Smart Home" technologies are being developed to enhance the safety of older consumers living in home and community-based settings. Such technologies can automatically perform such daily tasks as turning on lights when the person wakes at night; turning off ovens and stoves when residents forget to do so; reminding older people to take medication and monitoring whether they have done so; and alerting caregivers if an older person has fallen or is having other problems. Ongoing research and development efforts in this area must be supported and should include efforts to address relevant privacy issues.

Social Networking. Computer technology can lessen the isolation that long-term care consumers face when they live alone and suffer from disabling conditions that limit their ability to interact with others in their surrounding communities. Such technologies can allow homebound older people to join virtual, online communities where they can chat with friends; research health information at a variety of credible, medical Web sites; or find and contract for needed services in their local communities. A recent report in *The New York Times* suggests that technology entrepreneurs are showing increased interest in developing such social Web sites, which are geared exclusively to "graying" computer users.[40] With names like Eons, Rezoom, Multiply and Boomertown, these new sites hold great promise for their ability to connect long-term care recipients to the outside world and, in doing so, to improve the quality of their lives. These new sites are taking their place alongside more established Internet destinations, such as AARP's Web site, which are also responding to the need for social networking among older people by adding features that encourage interaction among their visitors.

Process Improvement Methodologies. Health IT systems allow long-term care providers to efficiently collect valuable data that can help improve quality in long-term care settings.

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[40] Richtel, Matt. 2007. "New Social Sites Cater to People of a Certain Age," *The New York Times*, September 11, 2007.

Data about the care provided to long-term care consumers can be used to measure outcomes, identify problem areas and help providers take concrete steps to improve quality. In addition to supporting internal quality assessments, health IT systems can also provide regulators with detailed reports, and can give researchers access to data that they can use to evaluate long-term progress. Most important, health IT systems can collect these data in a more efficient way than paper-based reporting systems and without imposing undo burdens on already overwhelmed staff members.

Provider Networks

Remote monitoring and other telemedicine innovations are still new concepts in long-term care, in part because providers often lack the expertise to launch technology programs. This lack of expertise could be alleviated by establishing networks and partnerships through which providers could cooperate on technology initiatives and through which more experienced providers could mentor those who have less familiarity or experience with these issues. For example, the VA, which is among the nation's most technologically savvy health care systems, has a wealth of knowledge to share with its peers. The agency currently provides in-home services to more than 5,000 veterans and has one of the largest remote monitoring programs in the nation, according to a U.S. Department of Commerce (DOC) report to the 2005 White House Conference on Aging. The VA system, through which nurses can monitor 150 patients at a time using "relatively inexpensive technology products," could provide a valuable model for other long-term care providers. [41]

Remaining Challenges and Barriers

In the process of developing and implementing health IT in long-term care settings, providers and other stakeholders will need to face important issues, including the following.

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[41] Office of Technology Policy, U.S. Department of Commerce Technology Administration. 2005. *Technology and Innovation in an Emerging Senior/Boomer Marketplace.* Prepared for 2005 White House Conference on Aging.

Privacy and Security. Concerns about privacy cannot be ignored by long-term care providers seeking to increase their use of technology. Telemedicine programs, for example, will need to ensure that their technologies stay true to the purpose for which they were originally designed: in this case, to increase consumers' sense of independence and autonomy, not decrease it. Likewise, those who develop and promote use of EHRs, PHRs and e-prescribing initiatives must assure all health consumers, including consumers of long-term care, that the personal health data they agree to store on computer networks and share with health professionals and other caregivers will remain safe. On an ethical level, the health system has a responsibility to assure the privacy and safety of this information. On a practical level, it is unlikely that adequate numbers of consumers will participate in health IT initiatives unless they are confident that their personal data will not end up in the wrong hands.

The Health Insurance Portability and Accountability Act of 1996 moved forward an important national discussion about the privacy of health records. However, this law does not represent the final word on privacy issues. The national conversation needs to continue and serious questions about the security of online medical records should be posed and answered. Measures must be taken to protect the privacy of consumer health records and, by extension, safeguard the identities of consumers whose personal information could be at risk if hackers violate Web-based EHR systems.

Interoperability. Because the greatest benefit of EHRs lies in the fact that they can be accessed by caregiving staff across a variety of settings, EHR systems must be designed with interoperability in mind. Establishing interoperability — this is, the ability of separate information systems to "talk" with one another — will require cooperative planning at many levels, as well as technical expertise to build networks that can connect diverse care settings. Even within each care setting, health IT systems will also need to be designed so that they can be used easily by a variety of health providers — including certified nursing assistants, dieticians, social workers and therapists — who may have different types of information to share about residents and varying levels of computer literacy.

Funding. Long-term care providers spend less than three percent of their total operating budgets on information technology. The money these providers do spend usually goes to support administrative functions like billing and scheduling, rather than care-related functions like EHRs and remote monitoring. Most long-term care facilities report that they have steered away from health IT because the capital resources needed to start such a system are too great or because they lack the evidence that such technology will improve quality or provide a return on investment. Clearly, the financial costs associated with health IT, and the human effort it takes to establish and maintain a health IT system, represent two obstacles to widespread adoption. Adequate funding of the costs for establishing EHRs and telemedicine systems — including grants, subsidized loans and bonuses to help small providers in underserved communities adopt technology — is essential if these high-tech tools are to become an integral part of the day-to-day care offered in a variety of care settings. A new pilot program, announced in November 2007 by HHS Secretary Mike Leavitt, will encourage small- to medium-sized physician practices to adopt EHRs. Conducted by the Centers for Medicare and Medicaid Services (CMS), the five-year demonstration will provide financial incentives to 1,200 physician groups that are using certified EHRs to meet certain clinical quality measures.

In the area of telemedicine, the Medicare-funded Health Buddy Program represents an important first step toward more flexible reimbursement policies for health technologies. The pilot program, based in Washington and Oregon, has distributed free, lunchbox-size computers to 2,000 Medicare patients who have diabetes, congestive heart failure or chronic obstructive pulmonary disease. Patients use the Healthy Buddy appliance at home to conduct a daily dialogue with their physicians and other health providers. During the course of each dialogue, the patient answers questions about his or her condition, receives coaching and information about preventive behaviors and transmits his or her vital signs through a secure Web site. Health Hero Network of Redwood City, California, which developed the Health Buddy, claims that the technology reduces hospitalizations because it allows physicians to spot problems and intervene early, before patients require a trip to the emergency room.

State Medicaid programs are also making strides in implementing health IT initiatives, according to a recent report from the HHS Office of Inspector General. The report found that 12 state Medicaid agencies have implemented a total of 16 health IT initiatives, including EHRs and remote disease monitoring, for their Medicaid populations. In addition, 25 state agencies are planning statewide health-information-exchange networks.[42]

Awareness and Participation. While this progress is laudable, the entrance of long-term care providers into technology-assisted care has only begun. Much more needs to be done. It is critically important that the interests and needs of long-term care consumers be part of health IT discussions and developments. Groups of long-term care providers have taken important steps in this regard by petitioning the Office of the National Coordinator for Health Information Technology and the Certification Commission for Healthcare Information Technology to include long-term care in the scope of their work, and by forming various industry workgroups to explore issues surrounding electronic health records, privacy and security of patient information and e-prescribing standards. In addition, organizations like the Center for Aging Services Technologies (CAST), which represents a coalition of more than 400 technology companies, aging-services organizations, businesses, research universities and government representatives, have a vital role to play in making sure that the interests of long-term care consumers are well represented as technology moves forward. To paraphrase CAST's mission statement, these organizations can help create a shared vision and a public awareness of how technologies can improve the quality of life for older people, establish pilot programs that can foster technology research and development, work to remove barriers to the implementation of proven solutions, and promote dialogue about standards to ensure interoperability and widespread access to aging-services technologies. All of these activities are sorely needed.[43]

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[42] Office of Inspector General. 2007. *State Medicaid Agencies' Initiatives on Health Information Technology and Health Information Exchange.* Washington, DC: U.S. Department of Health and Human Services.

[43] Visit the CAST Web site, at www.agingtech.org, to learn about specific long-term care pilots in this area.

Next Steps

Ever since IBM introduced its first personal computer in 1981, Americans have had a complicated relationship with technology. For some, that relationship has been a love affair, based on the conviction that there are few problems that can't be solved with a computer or other electronic gadget. For others, technology — and its potential to challenge us, steal our privacy and control our lives — has always been something to fear. As we attempt to create a future in which technology will be an integral part of high-quality long-term care provision, we need to remain open to the benefits that this technology can offer us and cautious about how we use technological tools. The Commission makes the following recommendations to encourage long-term care stakeholders to harness technology as a way to empower long-term care consumers and to improve the quality of care and services they receive.

TECHNOLOGY RECOMMENDATIONS

I. USING TECHNOLOGY TO ACHIEVE QUALITY

1. Promote information technology as one way to bring about quality improvement in long-term care.

2. Encourage the adoption and application of consumer-centric, continuous process improvement methodologies in long-term care. Health information technology (IT) can play a critical role in helping long-term care providers collect valuable data about the care they provide and then to use that data to measure, assess and improve the quality of care. In addition to supporting internal quality reviews, health IT can also help long-term care settings create detailed, useful reports for regulators and provide clinical data to researchers seeking to add valuable knowledge to the field of long-term care. Most important, it can accomplish these tasks in a more efficient way than paper-based reporting systems and without imposing additional burdens on already overwhelmed staff members.

3. Establish and enforce standards and methodologies to ensure that the privacy and security of a long-term care consumer's electronic health information is vigorously protected.

II. ESTABLISHING FEDERAL AND INDUSTRY LEADERSHIP

4. Establish federal and industry-wide leadership around the use of health IT in long-term care.

5. Strengthen and expand industry-wide, technology-based collaborative efforts such as the Center for Aging Services Technologies, the American Telemedicine Association and the Continua Alliance. In addition, encourage long-term care stakeholders to work with

stakeholders in the disability community to strengthen the nation's support for accelerated development of assistive technologies that can benefit young and old alike.

6. Create federal leadership entities and leadership positions to support technology in long-term care. These could include the addition of a Senior Technology and Aging Policy Analyst dedicated to aging services and long-term care within the White House Office of Science and Technology Policy; and the establishment of a well-positioned, well-staffed and well-funded interagency workgroup that would be charged with coordinating federal long-term care technology efforts.

7. Establish the Consortium on the Impact of Technology in Aging Health Services, proposed in S. 908 (introduced in 2007), to evaluate and advance the potential of new technologies that will help the United States prepare for the unprecedented growth of the older population and the impact this demographic shift will have on the nation's health care system. In order to be most effective, the consortium should include representatives from the long-term care community, align itself closely with other government agencies that address health IT issues, receive adequate funding and be required to collaborate with federal long-term care and research programs.

III. OPEN COMMUNICATION AND DATA SHARING

8. Promote information flow across care settings as a way to help transform health care. Every segment of health care — including acute care and long-term care — must commit itself to providing consumer-centered, quality care through a single, seamless system. Achieving this goal will require that health and long-term care professionals, technology firms, government researchers, policy makers and other stakeholders step beyond the lines that currently separate their sectors so that information and expertise can be easily shared.

9. Encourage the long-term care community to actively monitor existing and emerging innovations that can be applied to long-term care, and to develop additional strategies that promote innovation in care.

10. Facilitate more efficient technology transfer between federal government research institutions and the nation's private sector. The long-term care community should promote legislation that would specifically require existing mechanisms to support the transfer of long-term care and aging-related technologies between the public and private sectors.

11. Publicly recognize advances in long-term care technology carried out by academia, technology vendors and others. A "National Medal for Aging and Long-Term Care Technology" could bestow prestige on the recipient while stimulating awareness of the need for innovation and the existence of technology-related business opportunities within long-term care.

IV. REMOVING BARRIERS TO INNOVATION

12. Pursue sustainable funding models that accelerate the adoption of health IT in long-term care. Health IT adoption and utilization is an essential requirement for creating a state of continuous process improvement in long-term care. However, there is a significant lag between the time health IT investments are made and the time that benefits begin to accrue. Self sustaining funding models like revolving loan funds could effectively support the development of health IT and, in the process, help optimize quality in long-term care settings.

13. Reduce or remove barriers to innovation and the adoption of technology in long-term care. Identify, analyze and understand the social, economic and political dimensions of barriers to technology innovation and adoption in long-term care. These barriers include the lack of post-research financing to create marketable products and the delay in development of standards that support interoperability and market confidence.

14. Encourage the long-term care sector to play a leading role in removing these barriers to technology innovations. The process of changing laws, regulations, policies, economic incentives and socio-cultural norms is usually very long and requires committed resources. The long-term care sector should be prepared to shoulder this responsibility until federal resources become available. At that time, the strength of the existing leadership within the long-term care sector can ensure that a robust public-private partnership will emerge to further this work.

15. Identify and address the regulatory hurdles that impede the use of telemedicine and its reimbursement. Telemedicine, online consultation and other methods for extending the reach and availability of services can maximize the utilization of the long-term care workforce and help older people maintain independence.

16. Work with the Drug Enforcement Agency (DEA) and the Food and Drug Administration to find solutions that will permit safe and legally enforceable electronic prescribing of controlled substances, which are effective in relieving the pain associated with many chronic conditions experienced by older people. Considerable progress has been made in modifying archaic state laws and regulations that prohibited the use of electronic prescribing. However, the DEA has yet to create a framework for permitting electronic prescribing of controlled substances. Older consumers are disproportionately affected by this limitation.

V. ENCOURAGING INNOVATION AND RESEARCH

17. Support the development of longitudinal Personal Health Records (PHR), PHR-related standards and consumer-centric mechanisms for using PHRs to link long-term care providers and other settings. PHRs have the potential to become a key means for sharing patient information between different care settings. They can also support older people to remain independent for longer by providing those consumers with personal medical

decision support tools. Long-term care settings must be included in the development of future PHR-related use cases.

18. Support the foundational work required to create the standards, tools and infrastructure necessary to support health information exchange and interoperability. The work required is far removed from direct patient care and is slow to yield noticeable returns. However, it is absolutely essential to ensure that the nation can reap future benefits from its investments in health IT. For example, the need for a physical technology infrastructure supporting broadband communications and information exchange is a necessity if many home-based technologies that promise to keep older people independent are to be realized. Other countries have already committed themselves to making wireless broadband a ubiquitous offering. Municipalities in the United States are beginning to do the same and they should be encouraged to continue this effort.

19. Promote a research agenda that would evaluate the cost, quality and efficiency of applying information technology solutions to long-term care. Demonstration projects and evaluation research can help promote information technology adoption. The Agency for Health Research and Quality is one source of funding for objective outcomes studies on the use of health IT in long-term care; the Veterans Health Administration would an ideal test site for some of these investigations.

CHAPTER 4: FINANCE

When it began its work in 2004, the National Commission for Quality Long-Term Care accepted a simple mission: to draw attention to, and further a national discussion about, the current and looming crisis in long-term care and how the nation might respond to it. The Commission has issued this final report in an effort to share important information about that long-term care crisis and to describe a number of strategies that promise to help the nation improve the quality and accessibility of its long-term care services. Those strategies include:

- Transforming the culture of long-term care settings and placing the needs of consumers — not the needs of providers — at the heart of those settings.

- Devising a long-term care system that emphasizes quality of care *and* quality of life.

- Strengthening the long-term care workforce by improving training, upgrading working conditions and increasing compensation.

- Incorporating emerging technologies into home-based settings and long-term care facilities in order to maximize the independence of older consumers and make care provision more efficient.

In the process of exploring these and other strategies over the past three years, the Commission has had a valuable opportunity to hear from a variety of long-term care experts and to hold lively discussions about various approaches to improving long-term care. During each and every discussion, however, two unresolved questions hung in the air and still challenge Commission members. They are:

1. How will the nation cover the cost of researching, choosing, developing and implementing the quality improvement measures that the Commission has recommended?

2. How can the nation guarantee that every person or person with a disability who needs long-term care services will have full access to them?

Readers who are familiar with the current long-term care financing system will not be surprised by the Commission's conclusion that this system is not serving long-term care consumers or the nation very well. The disability that often triggers the need for long-term care is an insurable event. Yet, our nation has been unable to develop adequate insurance instruments to address the skyrocketing costs of disability in our rapidly aging society. Medicare, the primary health insurance program for people over age 65, covers very little long-term care. Private insurance for long-term care reaches only a very small portion of the population. And the Medicaid program, our health insurance safety net, pays for long-term care services only after beneficiaries spend down and impoverish themselves.

Clearly, we can do better. But doing better won't be simple or easy. Commission members know this from personal experience. After three years of work, the Commission has concluded that it could not recommend one specific long-term care financing model that met all members' criteria for quality, feasibility, fiscal responsibility and access. However, the Commission believes that it has taken a critical first step in identifying such a model by developing a philosophical framework that it hopes will help to launch a national discussion on this most important topic. It is the Commission's hope that this national discussion will lead to action that serves to improve the long-term care financing system so that the costs associated with chronic disease and disability can be shouldered equitably and so all Americans can have access to the services they need to live independently for as long as possible. Clearly, reform of our nation's long-term care policies and their financing must become a national priority.

Defining the Stakeholders

Disability at any age involves costs: costs to individuals, to families, to providers of long-term care services and to governmental entities. Before the nation can devise a system to cover those costs, policy makers must understand what role each stakeholder currently plays in the long-term care marketplace, what unique challenges they face and how an equitable long-term care financing system could serve their needs. Those stakeholders include:

Persons with disabilities. Long-term care is a key part of Americans' health and financial security. Virtually all people will have an experience with long-term care, whether that experience involves purchasing long-term care services for themselves or providing or purchasing such services for a friend or a family member. In addition, most people will come to long-term care after the onset of disability, whether that disability presents itself at birth, after a trauma or as a result of diseases associated with aging. At the onset of disability, many older people find themselves in the untenable position of having declining income and savings at the same time when disability-related expenses are mounting. This confluence of challenges brings with it a harsh reality: many frail older people simply do not have the financial resources to obtain the services they need, either in the community or in long-term care facilities.

Family and friends. The vast majority of long-term care is provided by "informal" caregivers, including spouses, children and neighbors who make great personal sacrifices in order to provide a range of services to frail older relatives and friends. The nation's need for unpaid caregivers is likely to increase in the future, as federal and state governments adopt "nursing home diversion" and rebalancing programs aimed at shifting long-term care spending from institutions to the community. Additionally, Commission members recognize that because of changes in the composition of the family, geographic mobility and other factors, an increasing number of persons will need care while families will have fewer younger members available to provide informal care. Aware that most consumers prefer to remain in their own homes for as long as possible, the Commission applauds the new interest in home and community-based services. However, Commission members also are

aware that such a shift will increase the costs — economic, emotional, physical and social — that caregivers currently pay in order to serve the majority of the nation's frail citizens. In many instances, caregivers who are compelled to constrain their workdays and turn down professional opportunities in the workplace may put their own retirement security at risk. Any attempts to reform long-term care must consider the needs of these unpaid caregivers and must make a meaningful investment in programs and services that support them in the important and valuable work that they do.

Communities. When policy makers think about designing a long-term care system that will serve consumers well, they sometimes overlook the fact that most persons with disabilities need an array of community supports that will enable them to live as independently as possible. Many of these supports are rather basic: they provide nutritious food, adequate housing, transportation, recreation, entertainment and readily accessible social services to persons in need. Every community in America is challenged to anticipate the needs of its citizens with disabilities and to build accessibility into all of the community's basic services. For example, communities can examine ways to create a technological infrastructure so that the needs of citizens with disabilities can be detected and addressed remotely. Disability requirements can be incorporated into housing construction and infrastructure, including universal design, curb cuts on sidewalks and technology in the home. Volunteer associations and government agencies can design their services to reflect the special needs for safety and the convenience of persons with disabilities. By incorporating these supports into their infrastructures, communities can serve persons who need assistance with daily activities while reducing personal and family costs. In addition, livable communities can remove barriers that create social isolation for older adults and people with disabilities.

Long-term care providers. Long-term care providers are obligated, both morally and legally, to provide quality care in a safe environment. To do so, however, these providers need adequate financial resources. Some providers are able to obtain these financial resources on their own by accessing sources of private philanthropy or by targeting their care and services to consumers who can afford to pay for them. However, these providers make up only a small minority of organizations and agencies serving frail older people today. The

majority of providers serve individuals who do not have the means to finance their own care. To carry out their missions, these providers depend on the often constrained reimbursements provided by state Medicaid programs. If the nation is serious about quality in long-term care, it must make an investment in long-term care that allows providers to make necessary improvements in their services, adequately train and compensate staff people who provide hands-on care, and incorporate into care settings the kind of technology that could improve quality and efficiency in long-term care settings.

States. Every state plays a vital role in overseeing long-term care quality and ensuring access, by the poorest among us, to needed care. Unfortunately, many states carry heavy economic burdens and struggle financially to maintain a wide range of state services in the face of limited resources and rising costs. As a result of these economic pressures, states are increasingly being forced to make difficult tradeoffs as they balance their citizens' competing needs. In some states, these competing interests bring with them resource shifts that can adversely affect long-term care financing levels. These shifts create an unintentional inequity among Americans with disabilities and create disturbing situations in which residents of one state may have adequate access to care when residents of a neighboring state do not. Such inequities impose geography-based burdens on individuals that simply are not fair.

Federal government. The Medicare program pays only a small portion of the nation's long-term care expenses, primarily covering limited home health services and a limited amount of skilled nursing care. Other federal programs, such as the Older Americans Act, also provide supports to those needing long-term care and their families. By far, however, the largest share of federal long-term care funds goes to the Medicaid program: the federal government and the states share the costs incurred through that program. Medicaid is the largest public payer of long-term care but it is available only to low-income Americans or those who have impoverished themselves. While many older people receive help from Medicaid dollars to pay for institutional long-term care, the federal government also approves some Medicaid home and community-based services waivers and has taken other steps that allow individuals across the country to remain in their homes and communities

while receiving long-term care services. The challenges facing the entire health care system — such as increasing costs — also face the Medicaid program.

Features of a Long-Term Financing System

The long-term care crisis affects every American; therefore, every segment of our society — and, specifically, the stakeholders mentioned above — has a role to play in addressing that crisis so that long-term care services become more available, affordable, effective and efficient. Without a doubt, we are all in this "together." Any workable solutions to the long-term care crisis will require commitment and hard work from individuals, the private sector and the public sector. Responsibility for financing the long-term care system should be shared by all of these stakeholders.

The staff and advisory council of the Georgetown University Long-Term Care Financing Project have been exploring strategies for creating a long-term care system that will best meet the nation's needs, both today and in the future. During the course of its work, the project has examined 12 separate proposals for long-term care financing and has identified four distinct strategies that should be considered as the nation attempts to design a new approach to providing quality long-term care.[44] Each of these strategies involves roles for individuals and the public and private sectors, but the balance and role of each vary depending on the approach. These strategies include:

Strategy #1: *Promoting private long-term care insurance while retaining public financing as a safety net.* Private insurers would play a larger role in paying for long-term care than they currently do. This approach could offer incentives, such as tax credits, to purchase private long-term care insurance. It may require changes to private insurance policies to make them more affordable and to cover individuals with pre-existing conditions. Individuals would have a greater role in planning for their long-term care, but the public safety net would be critical and would need to be adequate for all those who need it.

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[44] Feder, J., Komisar, H., and Friedland, R. 2007. *Long-Term Care Financing: Policy Options for the Future.* Washington, DC: Georgetown University Long-Term Care Financing Project.

Strategy #2: *Expanding the safety net for people with low-to-modest incomes, while expecting those who are able to rely on private financing.* A national floor of protection would be created for some individuals and some of the gaps in the current Medicaid program would be closed. Such an approach could remove some existing state-by-state variations in the Medicaid program. However, this approach would still be a safety net and not the same as insurance. Individuals with more financial resources who did not meet the safety-net eligibility criteria would use private financing, such as savings or private long-term care insurance, to pay for their long-term care. While there would be an expanded public safety net, a large number of individuals would need other financing options.

Strategy #3: *Establishing public catastrophic long-term care insurance, stimulating complementary private insurance to fill in the gap for those who can afford it and providing a safety net for those who cannot.* Public and private long-term care policies and programs would work together in a way that they often do not today. Under this approach, a public catastrophic program could provide coverage after an individual had already spent a certain dollar amount or length of time receiving benefits under a private long-term care insurance policy. Different models under this approach might vary in how closely they tie the availability of the public catastrophic coverage to the purchase of a private policy.

Strategy #4: *Establishing universal public long-term care insurance while supplementing that insurance with private financing and a public safety net.* Everyone would receive a basic foundation of coverage on which to build. For example, a public universal long-term care insurance program could provide a basic benefit to all who pay into the program, but would not cover all the services that an individual might need or cover services for as long as an individual might need them. Individuals could purchase private long-term care insurance policies to cover what the base program does not cover and to provide additional financial security against long-term care costs. The public safety net would provide coverage to those who met eligibility criteria and did not have other coverage. The public program could require individual contributions and could encourage innovation in private long-term care insurance policies, as would some of the other approaches.

The Commission is not recommending any particular long-term care financing approach, strategy or model. However, no matter what form an improved long-term care financing system takes, the Commission believes that it should include certain principles or essential characteristics. A financing system should: (1) focus on consumer needs and preferences; (2) include some consumer responsibility for health and some responsibility to save and plan for the cost of care, as well as measures to encourage and facilitate individual savings or planning to pay for future long-term care needs; (3) pool risks through insurance; (4) share responsibility among government, individuals and the private sector; (5) be national in focus; and (6) provide a strong safety net for the poor.

Focus on the Consumer

Of all the stakeholders mentioned above, the Commission was particularly concerned with one group: those people with disabilities who will be choosing and purchasing long-term care services today, next year and in the decades to come. These people, no matter what their age, face pressing challenges as they seek equal access to long-term care, as they shoulder the burdens of paying for such care and as they seek to receive needed services in the home and community-based settings of their choice.

Persons suffering from any disability require a range of supportive services. Most will require a basic selection of simple services, including nutrition, exercise, transportation, housing, safety and social services. For some, but not all, a range of medical, rehabilitation, pharmacological and economic supports, as well as supports to assist with daily activities, will be required. Health and long-term care providers have worked for many years to ensure that the first three of these supports — medical care, rehabilitation services and drug regimens — are available for those who need them. However, a concerted effort to provide the last two supports — economic support and assistance with daily activities — have been largely missing from the nation's public policy response to its citizen's long-term care needs. To fill this vacuum, the Commission supports the development of a long-term care financing system that adopts consumer direction and autonomy among its central features. Such a consumer-centered approach could mean more choice and control for the consumer.

In one possible scenario, a person's long-term care choices would no longer be limited to a one-size-fits-all set of services, as the current financing system often prescribes. Instead, beneficiaries of a new, consumer-centered financing system could receive financing assistance, in the form of a cash benefit, to purchase services that they — or their surrogate decision makers — determined were most needed. That cash benefit would be triggered when the person reached a predetermined level of disability. This cash benefit could be one of several options available to consumers; consumers could also choose to receive home care services that are coordinated by an agency or long-term care services that are provided in an institutional setting.

A consumer-centered financing system would respect an individual's ability to make decisions about his or her own care. It would also use public funds more efficiently to purchase those services that addressed a consumer's individual needs. Clearly, such a system would require careful fine-tuning before it was adopted: fine-tuning that might include setting criteria for the level of disability that would trigger benefits, ensuring alternatives for consumers who could not or did not feel capable of making care decisions, and resolving other important issues.

Consumer Planning

Consumer empowerment is a two-way street. As stated earlier, a long-term care financing system should empower consumers to take some responsibility for their long-term care. By the same token, however, that same system needs to encourage consumers to assume a certain level of responsibility for advance planning. That planning would help consumers to anticipate the possibility of disability, to take preventive measures that might help them avoid or decrease the severity of that disability, and to prepare financially for long-term care expenditures. Education and adequate, stable and flexible financing options are critical to encouraging consumers to plan for their long-term care needs.

Some level of consumer planning should be encouraged in two areas: health and financial planning.

- **_Health planning:_** First, consumers should be encouraged and offered financial incentives to adopt lifestyles that serve to preserve health, rather than put it at risk. Prevention and wellness are vital dimensions of individual and public planning for future long-term care needs. Recent studies have shown that participation in health promotion and disease prevention strategies add years of independence to an older person's life, reduce that person's level of disability and improve his or her quality of life.[45] Such participation should be actively promoted by appropriate public and private health agencies, which should carefully monitor the effectiveness of their outreach efforts. Consumers need to be educated about how the lifestyle decisions they make throughout their lives can affect how well they age. In addition, public and private organizations and agencies that offer long-term care insurance should be encouraged to offer incentives that would encourage individuals who purchase that insurance to participate in recommended health screenings and health-promotion activities.

- **_Financial planning:_** Second, the Commission affirms the responsibility of individuals to plan financially, throughout their lives as they are able, for the possibility that they may eventually experience disability and its accompanying economic consequences. All of the general financing strategies outlined above call for consumers to play a role in paying for their long-term care. Long-term care is an important part of an individual's financial security and should be part of retirement planning. Education is needed to help individuals understand their likelihood of needing long-term care, the costs of services, what public programs like Medicare will and will not cover, and what financing options and choices are available.

  Consumers also need more public and private financing options to help them plan and pay for their long-term care. However, it must be noted that financial planning alone will not necessarily provide an individual with adequate resources for long-term care. Consumers also need access to a range of tools — such as tax credits or affordable

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[45] AARP, American College of Sports Medicine, American Geriatrics Society, Centers for Disease Control and Prevention, National Institute on Aging and Robert Wood Johnson Foundation. 2001. _The National Blueprint: Increasing Physical Activity Among Adults Age 50 and Older._ Princeton, NJ: Robert Wood Johnson Foundation.

reverse mortgages — that will enable them to save. In addition, a number of strategies could be pursued at the federal level to harness the "power of compound interest" by encouraging individuals to start saving early for long-term care. Tax incentives, established to reward personal savings, could motivate younger people to set aside money today for services that they won't use for many decades. Tax incentives should be examined to determine who they would assist, if this assistance is efficiently and effectively directed to the people who need it, and the costs and benefits of such incentives.

Pooling and Spreading Risks

Both trauma-related disability and disability associated with age-related chronic illnesses and frailty are insurable events; that is, by paying a periodic premium, consumers can spread the cost of long-term care among a large pool of individuals and avoid the risk that long-term care costs will deplete their assets. Under the right circumstances, public and private insurers could be encouraged to create such risk pools and consumers could be encouraged to participate in them. Such insurance needs to be comprehensive and affordable. The universal public long-term care insurance strategy discussed above (Strategy #4) would be one example of building a large pool and spreading risk. Neither the private nor public sectors alone can provide the range of options needed; both public and private financing roles are important.

The nation currently does employ both public and private financing mechanisms for long-term care but, as noted, there are numerous problems that leave millions at risk. The strategies mentioned above call for a systematically enhanced partnership through which private long-term care insurance could be combined with publicly sponsored long-term care insurance and a residual safety-net of public funding for those who might otherwise fall through the cracks. There are several ways in which this enhanced public-private partnership could be developed:

- Publicly sponsored insurance could provide a floor for all, to be supplemented as needed or desired with private savings and/or long-term care insurance.

- A publicly engendered pool could be tapped after substantial individual expenditure that could be met by savings or participation in private long-term care insurance. (In either approach, public subsidies for the poor and a safety net would be needed.)

The Commission is not recommending a specific design for this public-private insurance coverage, including whether it should feature subsidies, mandates or "opt-outs." Depending on how such an insurance product is structured, it could reduce the cost of private long-term care insurance and encourage some consumers to consider purchasing it.

Shared Responsibility of Government, Individuals and the Private Sector
Any financing system should be affordable to individuals and to society as a whole, with shared responsibility among government, individuals and the private sector. No single stakeholder can finance long-term care alone. Individuals have an important role in planning, paying for and providing long-term care. The public sector has an important role in creating options and opportunities that the private sector alone cannot create. This sector can also help to ensure a long-term care safety net. The private sector has an important role in spurring innovation and options that the public sector alone could not create. The synergy and roles of all of these stakeholders are critical.

A National Focus
The crisis in long-term care is a national problem that must be addressed adequately and with equity for all Americans. A person's place of residence should not determine whether he or she receives adequate support to cope with disability. Instead, we need to carry on a national conversation about long-term care and to take national action, through carefully thought-out approaches, to ensure that all Americans receive the care and services they need in a setting that feels like home.

Safety Net
While individual responsibility should be encouraged, the Commission also recognizes that the occurrence of a disabling condition or the lack of financial resources is often beyond the control of an individual. Disability may still affect individuals who practiced health-

prevention strategies throughout their lives. In addition, disability may ensue because, through no fault of their own, individuals were unable to participate in those strategies. Likewise, the Commission recognizes that, due to lifelong financial challenges, some consumers will be unable to prepare economically for the costs of long-term care, either by saving on their own or by participating in other financial-planning activities. Individuals may also lack or have exhausted all of their other financing options.

Therefore the Commission asserts that all financial reform strategies must feature a public safety net that is designed to ensure that a consumer's inability to pay will never be a reason for that consumer's lack of access to needed care and services.

Demographic Considerations

The options described above, as well as other long-term care strategies, will have different value and applicability to the three distinct segments of the long-term care market:

- The *Silent Generation* (born before 1946): Some members of this generation are already experiencing frailty and disability; others will continue to do so through the next several decades. Those individuals who have not pre-funded their long-term care, either through savings or insurance, are unlikely to do so in their 60s, 70s, or 80s. Therefore, policy makers will need to develop a short-term approach to providing this generation with equitable access to long-term care services. This approach will be different from the approach policy makers will use to provide affordable long-term care access to subsequent generations.

- The *Baby Boom Generation* (born between 1946 and 1964): These individuals are likely to need long-term care services beginning around 2025. Members of this generation, who will begin turning 65 in 2011, have been largely responsible for sparking a nationwide discussion about long-term care financing because their unprecedented numbers will create unprecedented challenges for the long-term care system. Policy makers need to take action now to educate this population about the possibility of impending disability,

encourage them to begin planning immediately to shoulder at least some of the burden of long-term care expenses, and devise a reliable safety net that can provide adequately for those who cannot afford to pay those expenses.

- *Generation X and beyond* (born after 1965): Given advances in medical care and changes in public health trends such as obesity, it is difficult to predict the specific long-term care needs that individuals born after 1965 will have. However, we can be sure that any steps taken to shore up the long-term care nest eggs of the Baby Boom generation will also help the generations that follow. In addition, action to encourage members of this generation to adopt savings strategies early in life hold the greatest potential for harnessing the power of compound interest so that it can help future generations more easily afford the long-term care services they will need.

We Are Not Alone

Many nations in the world — the United Kingdom, France, Germany and Japan among them — have already experienced the demographic shift that the United States is now anticipating. While each of these nations has a different culture and different health care system, their experiences could help enrich our national conversation about the future of long-term care.[46]

Guiding Principles

In addition to the ideas and principles already discussed in this chapter, the Commission believes that any national discussion about long-term care financing should take into consideration the following principles, which were recently adopted by the Leadership Council of Aging Organizations (LCAO), a coalition of national nonprofit organizations concerned with the well-being of America's older population and committed to representing their interests in the policy-making arena. The Commission shares these principles in the same spirit in which LCAO developed them: "to provide a framework for focusing

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[46] For more information about international financing solutions, see Gleckman, H. 2007. *Financing Long-Term Care: Lessons from Abroad.* Center for Retirement Research at Boston College.

attention, generating discussion and crafting a solution to the problem in the near future." They include the following:

1. **National Problem, National Solution** — Recognize that although states, communities, families and individuals have important roles to play, long-term care financing is a national problem that requires a national solution.

2. **Universality with Limited Opt-Out** — Create a public program that allows all people, including individuals with disabilities and those near retirement, the opportunity to contribute to and prepare for the costs of long-term care. Make participation as convenient as possible, such as through an automatic payroll deduction, but give people the limited choice to opt out.

3. **Public-Private Partnership** — Provide a strong foundation of protection while providing opportunities for personal planning that include a role for private sector options. Government, individuals and the private sector have a shared responsibility.

4. **Affordability and Risk Pooling** — Provide for broad pooling of risk and appropriate low-income subsidies to make premiums affordable enough so that all people, regardless of income and health status, can participate.

5. **Fiscal Responsibility** — Provide actuarially sound funding, such as through voluntary premiums that build reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole.

6. **Relieve Pressure on Medicaid** — Provide additional long-term care funding mechanisms that will help to moderate future Medicaid expenditures while preserving the guaranteed safety net.

7. ***Consumer Choice and Control*** — Promote independence and dignity across the broad continuum of care by ensuring beneficiaries the right to control and choose what services they receive, how and where they are delivered and who provides them.

8. ***Support Family Caregivers*** — Recognize and support the central role families and other informal caregivers play in planning for and providing long-term care, including developing strategies to support working caregivers to maintain their financial security.

9. ***Invest in Quality Care and Quality of Life*** — Target funding to: ensure sufficient workforce training and compensation to reduce turnover and expand the workforce; strengthen oversight and enforcement to improve quality of life and quality of care in all settings; and bolster advocacy for those receiving long-term care services.

NEXT STEPS

Discussions about the best way to improve quality in long-term care didn't begin in 2004 with the inauguration of the National Commission for Quality Long-Term Care and those discussions must not end with this final report. True transformation of long-term care will require ongoing discussions among many stakeholders.

Providers and policy makers will need to sit down with consumers and their families, *really* listen to consumer needs and desires and work hand-in-hand with consumers to design a better long-term care system. All stakeholders — providers, lawmakers and consumers — will need to make tough decisions and agree to compromises about where money can be invested most wisely in order to create inviting, empowering and high-quality long-term care environments. Regulators, consumer advocates and providers will need to explore together the regulatory issues that the transformation process will inevitably raise. These issues, many of them controversial, will not be resolved overnight, nor will providers, policy makers, regulators, consumers and their families find it easy to reach consensus. However, the Commission believes that the process of building a consumer-centered long-term care system, however difficult, is worth the intense effort that it will require.

Commission members are hopeful that these discussions will continue to take place over the next months and years. In this report, we have called on Congress to hold hearings during 2008 that will investigate and recommend workable strategies to design and implement that system. We have urged the next President of the United States to provide the leadership necessary to launch a multifaceted transformation of long-term care. In addition, we note a provision in the Long-Term Care Quality and Modernization Act, which was recently introduced in the House of Representatives by Representatives Earl Pomeroy of North Dakota, Shelley Moore Capito of West Virginia and Tom Allen of Maine. The provision would establish a new, Long-Term Care Quality Advisory Commission, which would be

charged with developing, coordinating and facilitating the implementation of a national plan for long-term care quality improvement.

The National Commission for Quality Long-Term Care believes that efforts to continue discussions about long-term care quality are important. The Commission's intent has always been to shed light on the challenges facing the nation and to spark a national discussion about potential strategies to ensure quality long-term care and to guarantee that all Americans, regardless of economic status, have access to that care. Even though the Commission has officially finished its work, Commission members look forward to participating as fully as possible in that national discussion as it moves forward.