

April 2007

Strategies for Improving the Quality of Long-Term Care

Final Report

Prepared for

National Commission for Quality Long-Term Care
Washington, DC

Prepared by

Joshua M. Wiener, Ph.D.
Marc Freiman, Ph.D.
David Brown, M.A.
RTI International
701 13th Street, NW, Suite 750
Washington, DC 20005

RTI Project Number 0210634.000



RTI Project Number 0210634.000

Strategies for Improving the Quality of Long-Term Care

Final Report

April 2007

Prepared for

National Commission for Quality Long-Term Care
Washington, DC

Prepared by

Joshua M. Wiener, Ph.D.
Marc Freiman, Ph.D.
David Brown, M.A.
RTI International
701 13th Street, NW, Suite 750
Washington, DC 20005

The opinions expressed in this report are those of the authors and not necessarily those of the National Commission for Quality Long-Term Care, the funding organizations of the National Commission for Quality Long-Term Care or RTI International.

RTI International is a trade name of Research Triangle Institute.

CONTENTS

<u>Section</u>	<u>Page</u>
Executive Summary	vii
What Is Long-Term Care About?	vii
Status of Quality of Long-Term Care	vii
Strategies to Improve Quality of Care: How Do We Get There from Here?	viii
1. INTRODUCTION	1
2. QUALITY DOMAINS IN LONG-TERM CARE.....	3
The Nature of Long-Term Care: How Long-Term Care Is Different.....	3
Different Parts of the Elephant: Quality of Care and Quality of Life.....	4
Principles for Improving Quality in Long-Term Care.....	5
3. The Status of Quality of Care	7
Nursing Homes	7
Home Health Care.....	11
Home and Community-Based Services	12
4. Strategies to Improve the Quality of Long-Term Care.....	14
Mandatory Approaches That Are External to Providers.....	14
Voluntary Approaches That Are External to Providers.....	24
Voluntary Strategies That Are Internal to Providers	30

5.	CONCLUSIONS.....	33
	Quality Domains in Long-Term Care: What Is Important to Consider?	33
	The Status of Quality in Long-Term Care: How Will We Know If We Are Making Progress?.....	34
	Strategies to Improve Quality of Care: How Do We Get There From Here?.....	35
6.	References.....	43

LIST OF TABLES

<u>Number</u>	<u>Page</u>
ES-1 Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care	x
ES-2 Options for Improving Quality of Long-Term Care	xiii
3-1 Nursing Home Compare Quality Indicators and National Averages, 2006.....	8
3-2 Nursing Staff Hours per Resident Day, by Type of Nurse and National Averages.....	9
3-3 Most Frequently Cited Deficiencies in Nursing Facilities, 2005.....	10
3-4 Home Health Compare Quality Measures and National Averages, 2006	12
5-1 Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care	35
5-2 Options for Improving Quality of Long-Term Care	38

EXECUTIVE SUMMARY

Although the quality of care and life supplied by many long-term care providers is good or excellent, inadequate or poor care is too common. This paper addresses three areas that are important in improving quality of long-term care:

- What are the important areas of concern for quality in long-term care?
- What is the status of the quality of long-term care?
- What are the pros and cons of various strategies to improve the quality of long-term care? What are specific initiatives implied by these strategies?

What Is Long-Term Care About?

Long-term care is primarily about helping people with disabilities in their daily activities. Quality can be divided into two main domains:

- Quality of care refers to the technical competency of medical and nonmedical services.
- Quality of life refers to such factors as consumer choice and autonomy, dignity, individuality, comfort, and meaningful activity.

Most regulatory attention and research has focused on quality of care rather than quality of life. Because of the nature of long-term care, this one-sided approach is inadequate and neglects critical quality dimensions.

A variety of principles for improving quality in health and long-term care have been proposed. The Institute of Medicine panel on long-term care emphasizes the importance of ensuring that long-term care is consumer centered, providing consumers with information, developing multidimensional measures of quality, and addressing both quality of care and quality of life. The Institute of Medicine panel on health care focused on safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity as components of quality.

Status of Quality of Long-Term Care

Many nursing home facilities, assisted living facilities, home health agencies, personal care providers, adult day care programs, and respite care programs provide high-quality care. However, some providers do not. According to data from the nursing home Minimum Data Set, federal nursing home inspections, and the home health Outcome and Assessment Information Set:

- Five percent of long-stay nursing home residents have moderate to severe pain; 22 percent of short-stay (post-acute) nursing home residents have moderate to severe pain.
- Twelve percent of long-stay nursing home residents have pressure sores; 17 percent of short-stay (post-acute) residents have pressure sores.
- Six percent of nursing home residents are physically restrained.

- About 16 percent of nursing homes had quality of care problems that caused harm or immediate jeopardy to residents
- An average of 3.5 hours of nursing staff per resident day is provided in nursing homes, well below levels recommended by many experts.
- Twenty-one percent of home health agency patients had a need for urgent, unplanned medical care.

Over the past two decades, enormous progress has been made in developing quality measures for long-term care. In considering these measures, the following factors should be taken into account:

- Nursing homes and, to a substantial but lesser extent home health agencies, have been the focus of these data and measurement initiatives. A great deal of information is publicly available about individual facilities and agencies.
- In contrast, no data on quality are available at the national and almost no data are available at state levels for nonskilled home care, assisted living facilities, and other residential settings. This partly reflects the fact that states rather than the federal government have responsibility for these services.
- Quality initiatives in long-term care have focused on quality of care rather than quality of life. Thus, we know much more about individuals' ability to transfer from their bed to a chair than we do about whether nursing facility residents believe that they have control over their lives.

Strategies to Improve Quality of Care: How Do We Get There from Here?

A large number of strategies have been proposed to improve quality of care. Some use the power of government to force providers to do certain things; others rely more on market incentives or the internal goodwill of providers to improve their services. These approaches, which are summarized along with their pros and cons on *Table ES-1*, include the following:

- Mandatory approaches that are external to providers:
 - Strengthening the regulatory process.
 - Strengthening the caregiving workforce (e.g., establishing minimum staffing ratios in nursing homes).
- Voluntary approaches that are external to providers:
 - Providing consumers and others with more information about the quality of services provided by individual providers.
 - Strengthening consumer advocacy.
 - Changing Medicare and Medicaid reimbursement systems, including the system of incentives they generate.

- Voluntary strategies that are internal to providers:
 - Developing and implementing practice guidelines.
 - Changing the organizational culture of long-term care providers.

Table ES-1. Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care

Strategy	Pros	Cons	Other Comments
Mandatory Approaches that are External to Providers			
Strengthening the regulatory process	Builds on large existing system of quality assurance for nursing facilities and home health agencies. Great deal of data available. Main approach used in many other countries.	Many regulations address paperwork and structural requirements rather than outcomes. Nursing home regulations inconsistently interpreted and applied across geographic areas. May stifle innovation. Enforcement often weak for nursing facilities.	Federal government dominates regulation of nursing facilities and home health agencies; states dominate regulation of other services. Currently, extensive regulation for nursing facilities and home health agencies, but little regulation of home and community-based services.
Strengthening the caregiver workforce	Current staffing in nursing facilities below recommended levels. Training requirements for paraprofessional staff minimal or absent. Workers receive low wages and few fringe benefits, making recruitment and retention difficult.	Organization and management of services also very important. Expensive to implement. No research on effects of training on quality. Little research on effects of higher wages and benefits on quality of care. May create barriers to entry.	Long-run demographic changes will make recruitment and retention more difficult over time.

(continued)

Table ES-1. Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care (Continued)

Strategy	Pros	Cons	Other Comments
Voluntary Approaches that are External to Providers			
Providing consumers with more information	<p>The Centers for Medicare & Medicaid Services (CMS) provides a great deal of nursing home and home health information to consumers on websites.</p> <p>Makes market work better by encouraging competition on quality.</p> <p>For current nursing home and home health care, low-cost initiative.</p>	<p>Little research evidence on the effectiveness of this approach.</p> <p>Structural aspects of market may reduce possibility of competition on quality.</p> <p>Consumers may not be able to use information.</p> <p>Current data are focused on quality of care rather than quality of life.</p>	<p>Little or no quality data available for home and community-based services, including assisted living facilities.</p>
Strengthening consumer advocacy	<p>Provides a counterbalance to nursing home industry.</p> <p>Represents views of consumers.</p> <p>Provides resolution to individual complaints.</p>	<p>No research on effectiveness.</p> <p>Volunteers often lack technical expertise.</p> <p>Fear of retaliation by providers may limit complaints. By consumers.</p>	<p>Most existing consumer advocacy on quality issues focuses on nursing homes rather than home and community-based services.</p>
Reforming the payment systems for Medicare and Medicaid	<p>A reformed payment system could provide incentives for quality care and a payment level sufficient to cover the costs of efficient provision of quality care.</p> <p>Government can change payment system.</p> <p>Providers depend heavily on government financing, making them sensitive to government reimbursement system.</p>	<p>Little research evidence on the effectiveness of this approach.</p>	<p>This is a growing area of experimentation and demonstration.</p>

(continued)

Table ES-1. Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care (Continued)

Voluntary Strategies that are Internal to Providers			
Developing and implementing practice guidelines	Low-tech aspects of long-term care make guidelines potentially very useful. Many guidelines already exist.	Some guidelines raise costs. Accurate reporting on use of guidelines may expose providers to surveyor sanctions. Limited federal and state government policy levers.	Most guidelines geared to quality of care rather than quality of life, and to nursing homes.
Changing the organizational culture of long-term care providers	Systematically changes culture of care to focus on consumer needs and empowering workers. Addresses many critiques of nursing homes.	Little research on effectiveness. Replicability unclear. May result in higher costs. Limited federal and state policy levers.	Focus has been on nursing homes; little attention on home health or home and community-based services.

In evaluating these different strategies, the following factors should be taken into account:

- Long-term care is a shared responsibility among the federal and state governments, providers, and consumers. The federal and state governments share the regulatory responsibilities.
- Federal and state government regulations are now the main policy mechanisms to ensure quality of care and quality of life in long-term care, especially for nursing home services. Advocates of regulation believe that enforcement is too lax; opponents believe that regulation does not address important quality issues and is too rigid.
- Data to measure quality are relatively well developed for nursing homes and home health agencies, but are almost entirely lacking for a wide range of home and community-based services.
- Several options for reform—including strengthening the caregiving workforce, changes in Medicare and Medicaid reimbursement systems, and developing and implementing practice guidelines—require substantially more resources that cost money. Because of the heavy reliance on the public sector, implementing these options will require increased federal and state spending.
- Despite the plethora of possible approaches to improve quality of care, the existing research literature does not provide much guidance about their relative effectiveness.

- Many quality initiatives are geared to punishing or avoiding inferior-quality care, rather than establishing incentives for providers to provide good- or high-quality care.
- Several of the strategies for improving quality presuppose a relatively sophisticated ability on the part of nursing homes and other long-term care providers to develop, analyze, and use data and then to implement management changes based on those data. This may be an inaccurate assumption.
- The political saliency of long-term care quality issues and the consistency of government attentiveness to the issue are uneven.

Table ES-2 presents a list of possible actions derived from the different strategies.

Table ES-2. Options for Improving Quality of Long-Term Care

Mandatory Approaches that are External to Providers

Reform the regulatory process

- Increase funding for the federal survey and certification process for nursing homes and home health agencies.
- Further standardize the inspection process to decrease geographic and surveyor variation in the citation of nursing home deficiencies.
- More aggressively enforce federal and state quality standards, with the goal of forcing poor-quality providers to close or change ownership. Increase use of intermediate sanctions and receiverships.
- Reduce regulatory burdens on consistently high-quality facilities (e.g., survey high-quality facilities less often).
- Increase the regulatory focus on outcomes. Review existing federal and state regulations to reduce unnecessary paperwork and micromanaging of long-term care providers.
- Review federal and state regulations to identify requirements that adversely affect quality of life in nursing homes and residential care facilities.
- Monitor quality of home and community-based services more systematically.
- Fund and conduct research on the effect of the regulatory process on quality of nursing home care and home and community-based services.

Strengthening the caregiver workforce

- Establish quantitative minimum staffing levels in nursing homes at least as high as the national average, if not higher. Establish minimum staffing levels for registered nurses in nursing homes that are higher than the national average.
- Increase state and federal minimum training requirements for certified nurse assistants and home health aides.
- Impose and strengthen state minimum training requirements for nonskilled workers in residential care facilities and home care.
- Establish foundation and federal/state programs to recruit staff to long-term care and to train the long-term care workforce.
- Increase wages and benefits for long-term care workers through Medicare and Medicaid wage pass-throughs.
- Increase federal funding for training informal caregivers under the U.S. Administration on Aging's National Family Caregiver Support Program and the Alzheimer's Disease Demonstration Grants to States program.
- Fund and conduct research on the determinants of recruitment and retention in long-term care and its effect on quality.

(continued)

Table ES-2. Options for Improving Quality of Long-Term Care (Continued)

Voluntary Approaches that are External to Providers

Providing consumers with more information

- More highly publicize CMS’s Nursing Home Compare and Home Health Compare websites.
 - Continue to refine the Nursing Home Compare and Home Health Compare websites, adding more measures that focus on quality of life. Work towards measures of quality that consumers can easily understand
 - Developing consumer-information websites for home care and residential care facilities at the state level.
 - Complete the development and consider implementation of the Nursing Home Consumer Assessment of Health Plans Survey.
 - Fund and conduct research on the effect of consumer information on quality of care.
-

Reforming the payment systems for Medicare and Medicaid

- Ensure that the design of prospective payment systems for Medicare and Medicaid does not include incentives to reduce expenditures for client care without regard to quality.
 - Ensure that Medicare and Medicaid reimbursement levels are adequate to provide high-quality care.
 - Refine nursing home and home health prospective payments systems to incorporate some financial incentives for higher-quality care. Extend CMS pay-for-performance demonstrations to all major portions of the long-term care services system.
 - Fund and conduct research on the effect of Medicare and Medicaid reimbursement on quality in nursing homes and other long-term care providers.
-

Strengthening consumer advocacy

- Increase funding for the U.S. Administration on Aging’s Long-Term Care Ombudsman program.
 - Establish foundation programs to support consumer advocates for long-term care quality.
-

Voluntary Strategies that are Internal to Providers

Developing and implementing practice guidelines

- Disseminate more widely practice guidelines and protocols.
 - Fund and conduct research to develop cost-effective practice protocols.
-

Changing the organizational culture of long-term care providers

- Develop and demonstrate new methods to re-orient the overall culture and process of care in nursing homes and other providers to improve the quality of life of residents and clients.
 - Fund research on the effectiveness of culture change on the quality and cost of long-term care.
-

1. INTRODUCTION

Concern about poor quality of care by nursing homes and other long-term care providers dates back to the 1970s, if not earlier (New York State Moreland Act Commission, 1975; U.S. Senate Special Committee on Aging, 1974; Wiener, 1981). This unease about quality is not limited to the United States, but exists in a number of countries (Wiener et al., 2007). In the last major national legislative response to perceived problems in the United States, the Omnibus Budget Reconciliation Act of 1987 (OBRA '87) raised quality of care standards for nursing facilities and home health agencies that participate in Medicare and Medicaid and strengthened federal and state oversight. Following the implementation of OBRA '87, several studies found improvement in the quality of care in nursing facilities, especially related to the use of physical and chemical restraints, prevalence of dehydration and stasis ulcers, and use of catheters (Fries et al., 1997; Hawes et al., 1997; Phillips et al., 1996, 1997; Zhang & Grabowski, 2004).

Despite these improvements, there are substantial signs of continuing poor-quality care in nursing facilities and problematic government oversight (Institute of Medicine, 2001a). In one study, 30 percent of older people reported that they would rather die than move to a nursing home (Mattimore et al., 1997). In the most recent of a widely cited series of studies, the U.S. Government Accountability Office (GAO, 2005) found that there was a significant decrease in the proportion of nursing homes with serious quality problems, from about 29 percent in 1999 to about 16 percent by January 2005. However, GAO reported that this trend masked two important and continuing concerns: inconsistency among state surveyors in conducting surveys and understatement by state surveyors of serious deficiencies (GAO, 2005). In addition, the GAO (2007) found that many poor quality facilities continued to cycle in and out of compliance on subsequent surveys. The Administration on Aging's national ombudsman reporting system received more than 230,000 complaints in 2005 concerning nursing facility residents' quality of care, quality-of-life problems, or residents' rights (Administration on Aging, 2007).

One of the policy rationales for expanding home and community-based services is that the quality of care of these services is better than in nursing homes. However, much less is known about the quality of home and community-based services. Although people who use home care typically report high levels of satisfaction, measuring and ensuring quality of care in the home and community setting is at a fairly early level of development compared to nursing home care (Geron, 1996; Kane & Huck, 2000; Khatutsky, Anderson, & Wiener, 2006; Montgomery & Kosloski, 1995; Weissert et al., 1990). Recent newspaper accounts of poor quality of care in assisted living facilities have increased concern about the care provided in those settings (Appleby, 2004; Coates 2007; Dilanian, 2007; McCoy, 2004; McCoy & Appleby, 2004).

The purpose of this paper is to provide background information that will be useful for identifying initiatives to improve quality in nursing facilities, home health, nonskilled home care, and assisted living facilities. The paper is divided into the following sections:

- A discussion of the domains of long-term care quality, which emphasizes that it is a unique combination of medical and social care that should be individualized to personal preferences.

- An analysis of what is known about the quality of long-term care and initiatives to develop measures of it.
- A review of strategies that have been proposed and are being used to improve the quality of long-term care.
- A conclusion, which summarizes and draws implications from the earlier sections.

2. QUALITY DOMAINS IN LONG-TERM CARE

In determining strategies for quality improvement, it is critical to understand the unique character of long-term care, the domains of concern, and the principles that have been proposed for improving quality in long-term care. They form the context for the debates over strategies to achieve improvements.

The Nature of Long-Term Care: How Long-Term Care Is Different

Long-term care has a number of characteristics that both connect it to and separate it from acute medical care:

- *Long-term care is mostly about social functioning.* Long-term care is the help needed to cope when physical and mental disabilities impair the capacity to perform the activities of everyday life, such as eating, bathing, and dressing; going shopping; managing money; and using the telephone. While these disabilities are the consequence of disease, such as osteoporosis, heart disease, multiple sclerosis, and Alzheimer's disease, long-term care is principally about managing and reducing functional impairments rather than managing disease processes. Thus, a great deal of long-term care does not involve highly technical medical services that must be provided by physicians or registered nurses; social services provided by relatively low-level trained staff constitute the large majority of paid care. Despite the social nature of much of the care, most public funding is through Medicare and Medicaid, two major sources of funding for medical care.
- *Long-term care needs to connect with acute care.* Although people with long-term care needs are not necessarily "sick" and do not necessarily require intensive medical services most of the time, older and younger people with disabilities tend to have high levels of use of acute care services (Alexih, Corea, & Kennell, 1995; Anderson & Hovarth, 2004; Komisar, Hunt-McCool, & Feder, 1997-1998). Thus, coordinating and integrating with the medical care sector is very important to meet the needs of people with disabilities.
- *Long-term care is about how we live our lives.* Because long-term care includes such fundamental and intimate tasks as bathing, dressing, and going to the toilet and because it affects how people live their lives over an extended period, it is an intensely personal service. Historically, the goals of long-term care were limited to keeping people with disabilities safe, clean, and well fed. More recently, this narrow conception has been rejected in favor of goals that maximize independence and self-sufficiency (Wiener & Sullivan, 1995). Increasingly, the goals of the service system are defined as providing access, to the extent possible, to the same freedoms and life enjoyed by nondisabled persons. This means integrating individuals with disabilities into community life, providing consumer choice and control, and tailoring services to the needs and preferences of individuals.
- *Long-term care includes nursing home care but is much broader.* The vast majority of people with disabilities, even relatively severe disabilities, live in the community rather than in nursing homes (Rogers & Komisar, 2003). Most people in the community receive their care from family and friends (usually with no

training) rather than from paid caregivers (Johnson & Wiener, 2006; Liu, Manton, & Aragon, 2000; Spillman & Pezzin, 2000). Only a small minority of older people with disabilities in the community received paid home and community-based care, such as personal care, homemaker services, and adult day care (Johnson & Wiener, 2006). While long-term care for older people dominates public policy and use of nursing homes, approximately one third of people with disabilities are under age 65 (Rogers & Komisar, 2003). The younger population with disabilities has some goals that are different from older people (e.g., employment and education).

Different Parts of the Elephant: Quality of Care and Quality of Life

Given the characteristics of long-term care, the domains of quality are often divided into quality of care and quality of life. While related, these domains are analytically separate and address separate parts of the care experience.

In terms of quality of care, a major focus of long-term care is on health and safety, including potential markers of poor quality such as dehydration, urinary tract infections, malnutrition, bedsores, excessive use of hypnotics and antipsychotic medications, undertreatment of depression, weight loss, and uncontrolled pain. For example, quality of care assessments include whether nursing homes carefully help residents with eating, whether there is adequate staffing to assist residents at mealtime, and whether residents maintain an appropriate weight. As discussed below, the vast majority of existing regulations and quality measures focus on quality of care.

In contrast, quality of life refers to much more intangible factors, such as autonomy, dignity, individuality, comfort, meaningful activity and relationships, a sense of security, and spiritual well-being (National Citizens' Coalition for Nursing Home Reform, 1985; Noelker & Harel, 2000). These factors are, by definition, subjective, but they are critical to living a good and meaningful life. To continue with the feeding example, quality of life refers to the tastiness of the food, the ability to choose meals that fit with personal preferences and ethnic heritage, the friendliness and patience of the staff helping with feeding, and the willingness of the staff to let residents feed themselves to the extent possible, even if it takes additional time.

An important hypothesis articulated by some advocates of assisted living and consumer-directed services is that there may be a tradeoff between quality of care and quality of life (Kane, 2001, 2003). As Rosalie Kane of the University of Minnesota puts it:

One little-tested assumption is that safety—defined vaguely or not at all—is the be-all and end-all of long-term care. Embedded in most of our rules and regulations is the idea that long-term care should aspire to the best quality of life *as is consistent with health and safety*. But ordinary people may prefer the best health and safety outcomes possible *that are consistent with a meaningful quality of life* (Kane, 2001).

Thus, for example, an individual with diabetes at the end of life may want to eat candy because it tastes good, even though doing so is medically undesirable. The negotiated risk agreements in some assisted living facilities, where informed consumers or their agents explicitly accept risks

and the possibility of adverse outcomes to achieve quality of life goals, are an effort to address these tradeoffs (Jenkins et al., 2006).

Principles for Improving Quality in Long-Term Care

Fundamentally, initiatives to improve quality in long-term care must be judged against a set of principles that are a mix of value statements and empirically-based assumptions. The Institute of Medicine (2001b) report on the quality of health care described six characteristics that high-quality health care should have, and these characteristics are relevant to long-term care as well. This framework, widely used in acute health care, holds that high-quality care should be:

- *Safe*—avoiding injuries to patients from the care that is intended to help them.
- *Effective*—providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively).
- *Patient-centered*—providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- *Timely*—reducing waits and sometimes harmful delays for both those who receive and those who give care.
- *Efficient*—avoiding waste, including waste of equipment, supplies, ideas, and energy.
- *Equitable*—providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Another set of related principles guided the work of the Institute of Medicine (2001a) panel on improving quality in long-term care:

- Long-term care should be consumer centered rather than solely provider centered.
- A system of consumer-centered long-term care should be structured to serve people with diverse characteristics and preferences.
- Reliable and current information about the options available and the quality of care provided should be easily accessible to allow people to make informed choices about long-term care.
- Access to long-term care services is both a quality-of-care and a quality-of-life issue.
- Measures of quality of care should incorporate its many dimensions, especially quality of life.
- Providers should be held accountable for their performance in providing high-quality long-term care, including the outcomes of care that they could affect.
- A motivated, capable, and sufficient workforce is critical to quality long-term care.

- Improving the quality of long-term care requires sustained government commitment to develop and implement fair, effective regulatory and financing policies.
- Improving quality of care must be an ongoing objective. Building the capacity for high-quality long-term care depends on improved knowledge of the practices and policies that contribute to the well-being of people using that care.

3. THE STATUS OF QUALITY OF CARE

This section summarizes what is known about the quality of long-term care in the United States. Valid, reliable, and timely data about the care that consumers receive are fundamental to all strategies for improving quality and to assessing success over time. The availability of data varies greatly across provider types. Although not perfect, a great deal of data is available about nursing home residents and home health patients and the outcomes of their care. No other country has invested as heavily in regularly collecting individual-level data on the functional and medical status of nursing home and home health consumers and uses it to measure quality (Wiener et al., 2007). Comparable data are lacking for nonskilled home care and residential care facilities (e.g., assisted living facilities). Developing such data for those services would require a major investment in research and data collection by national and state governments.

Nursing Homes

As would be expected from the volume of public expenditures and the history of problematic quality of care, a great deal of research has focused on developing quality measures for nursing home care, mostly sponsored by the federal government. As part of its oversight of nursing homes, the Centers for Medicare & Medicaid Services (CMS) operates a highly popular website, Nursing Home Compare, <http://www.medicare.gov/NHCompare>, which provides three sets of information about quality of care for nursing facilities that participate in Medicare and Medicaid: minimum data set quality indicators, staffing data, and inspection reports.

Minimum Data Set Quality Indicators. Key data about all nursing home residents (including private pay residents) are collected as part of the federally mandated minimum data set (MDS), which gathers functional and medical information on residents on a periodic basis. MDS data are used to construct quantitative “quality indicators” (Zimmerman et al., 1995). CMS uses these quality indicators as part of the survey and certification process, and makes 19 of them available to the public on its Nursing Home Compare website (***Table 3-1***). These indicators are divided into those that apply to people who have long-term or chronic care needs and those that apply to people who use nursing homes only for short stays. Importantly, there is no summary or overall rating or ranking of facilities. The measures appear to be correlated with other measures of quality. For example, Carter and Porell (2006) found that variations in hospitalization risk among nursing home residents were explained in part by facility performance on quality indicators.

Table 3-1. Nursing Home Compare Quality Indicators and National Averages, 2006

Indicator	National Average (%)
Long-Term (Chronic Care) Measures	
Percentage of residents given influenza vaccination during the flu season	87
Percentage of residents who were assessed and given pneumococcal vaccination	75
Percentage of residents whose need for help with daily activities has increased	16
Percentage of residents who have moderate to severe pain	5
Percentage of high-risk residents who have pressure sores	12
Percentage of low-risk residents who have pressure sores	2
Percentage of residents who were physically restrained	6
Percentage of residents who are more depressed or anxious	14
Percentage of low-risk residents who lose control of their bowels or bladder	48
Percentage of residents who have/had a catheter inserted and left in their bladder	6
Percentage of residents who spent most of their time in bed or in a chair	4
Percentage of residents whose ability to move about in and around their room got worse	12
Percentage of residents with a urinary tract infection	9
Percentage of residents who lose too much weight	8
Short-Stay (Post-Acute) Measures	
Percentage of short-stay residents given influenza vaccination during the flu season	73
Percentage of short-stay residents who were assessed and given pneumococcal vaccination	66
Percentage of short-stay residents with delirium	2
Percentage of short-stay residents who had moderate to severe pain	22
Percentage of short-stay residents with pressure sores	17

Source: Nursing Home Compare website, <http://www.medicare.gov/NHCompare>, accessed on 4/9/07.

The ratings under these measures are determined by counting nursing facility residents with each condition or problem and calculating the ratio of those residents to all residents of the facility at risk for the condition or problem (Abt Associates, 2004). All measures are risk adjusted.

These quality measures have two principal advantages:

- *They are the result of years of careful research funded by CMS.*
- *They focus on resident “outcomes” rather than the structural characteristics of the nursing home or the processes by which the nursing home provides care.* Thus, the measures leave how to accomplish the outcomes to the individual nursing home, avoiding micromanagement.

However, several concerns have been voiced about the use of MDS data for quality assurance purposes:

- *The MDS data may not be accurate, especially now that they are being used for regulatory and payment purposes as well as care planning.* Different processes of data collection across facilities may produce different results (Harrington et al., 2003). A key issue is that facility staff fill out the MDS and staff have strong incentives not to report problems.

- *Quality indicators could benefit from better analysis and refinement with regard to their validity and reliability* Some nursing homes may do well according to some indicators and poorly according to others, making summarizing the overall performance of a facility into a single score problematic, which limits their utility for consumers (Arling et al., 2005).
- *The relatively small size of most nursing homes and the modest prevalence of most quality problems create difficult statistical issues in determining which facilities are providing poor quality of care.* For example, some of the more serious quality indicators, such as decubitus ulcers, do not involve many residents, even in poor facilities. Given the relatively small number of residents in nursing homes (the average facility has about 90 residents), random variation in the prevalence of decubitus ulcers may be substantial, thus making it difficult to distinguish good from fair or poor facilities. Risk adjustment is statistically complicated and open to methodological challenge. In the end, facilities can only be held accountable for the care they provide, not their outcomes.

Staffing Data. Inadequate staffing is one of the most common complaints about nursing home care. The CMS Nursing Home Compare website provides the number of hours per resident per day for three categories of staff (**Table 3-2**).

Table 3-2. Nursing Staff Hours per Resident Day, by Type of Nurse and National Averages

Staffing	Hours
Registered nurse hours per resident day	0.5
Licensed practical nurse/licensed vocational nurse hours per resident day	0.7
Certified nurse assistant hours per resident day	2.3
Total nursing staff hours per resident day	3.5

Source: Nursing Home Compare website, <http://www.medicare.gov/NHCompare>, accessed on 4/9/07.

The California Nursing Home Search website, <http://www.calnhs.org>, sponsored by the California Health Care Foundation, also includes data on staff turnover rates compared to the state average, average wages for nursing assistants compared to the regional average, and total expenditures for direct and indirect nursing care compared to the regional average (Harrington et al., 2002).

The main advantage of these staffing data is that they provide a first approximation of the amount of resources available to care for residents. Although this staffing information does provide some potential for comparison among facilities, there are three important limitations on its use:

- *There is no “risk adjustment” to these staffing levels to account for the level of care needs of the residents of the facility.* Although the numbers of patients in each facility are reported, there is no way to know the severity of their conditions and make an informed judgment as to the actual demand placed on the staff.

- *The staffing information is provided by the facility without verification by CMS or state inspectors and may be either inaccurate or out of date.* For example, it is widely believed that many nursing homes increase staffing during the period when they expect to be inspected.
- *The staffing data include nursing staff who have administrative as well as direct care responsibilities.* Thus, the amount of staff available to actually provide care is likely to be less than the numbers would indicate.

Inspection Data. National inspection (also known as survey and certification) data on nursing homes are consolidated in the Online Survey, Certification and Reporting (OSCAR) system maintained by CMS. OSCAR compiles all data elements collected by surveyors during the inspection survey, which is conducted to certify compliance with the requirements for participation in the Medicare and Medicaid programs.

While deficiency citations from current and recent past federal inspections and complaints are available on Nursing Home Compare, it does not present detailed national prevalence of these problems. Harrington, Carrillo, and LaCava (2006) analyzed national federal nursing home inspection data for 2005, when there was an average of 7.1 deficiencies per facility. **Table 3-3** presents the national percentage of facilities with citations for the 10 categories covered by the inspections that were most frequently cited for deficiencies. In 2005, about 16 percent of facilities received were cited for quality of care problems that that caused harm or immediate jeopardy to residents (Government Accountability Office [GAO] 2005). Some other websites, such as the California Nursing Home Search, <http://www.calnhs.org>, also include data on compliance with state licensure requirements.

Table 3-3. Most Frequently Cited Deficiencies in Nursing Facilities, 2005

Category	Percentage of facilities with deficiencies
Food sanitation	34.7
Quality of care	29.5
Professional standards	28.1
Accidents	23.4
Accident prevention	22.1
Housekeeping	21.8
Comprehensive care plans	19.5
Infection control	16.7
Pressure sores	16.2
Dignity	15.8

Source: Harrington, Carrillo, & LaCava, 2006.

The advantage of these inspection data is that they capture information related to the primary quality assurance mechanism in the United States. In addition, the federal standards are comprehensive in their scope. Despite these advantages, there are issues with the data:

- Although a major improvement over prior standards, the current requirements still focus on process, procedures, and policies rather than on the outcomes or important processes of care.
- There is strong reason to believe that the likelihood of citations varies greatly across geographic areas and across surveyors, independent of the quality of care

provided. Thus, a facility in one location may be given a citation, while a similar facility doing the same things may not be given a citation in another location.

Other Measures of Nursing Home Care. While the MDS and the survey and certification system provide a great deal of information about nursing home care, they are limited primarily to quality of care rather than quality of life. There are other sources that attempt to measure the quality of nursing homes:

- *Administration on Aging Long-Term Care Ombudsman's complaint data.* The Administration on Aging's Ombudsman Program receives and investigates complaints about nursing homes. In 2005, there were 15,814 complaints alleging abuse, gross neglect, or exploitation; 9,110 complaints concerning rehabilitation or maintenance of function; and 1,247 complaints about chemical and physical restraints (Administration on Aging, 2007). The main advantage of these data is that they are an indication of quality as perceived by the consumer.
- *Nursing Home Consumer Assessment of Health Plans Survey (NH-CAHPS).* NH-CAHPS is an initiative by the Agency for Healthcare Research and Quality to adapt the concept of consumer satisfaction surveys to nursing homes (Bernard, Hampton, & Kreling, 2003; RTI International, 2003). While theoretically appealing, NH-CAHPS faces substantial methodological challenges, including the difficulties of administering it to the high percentage of nursing home residents who are cognitively impaired.
- *Quality of life in nursing homes.* Quality of life in long-term care, including in nursing homes, has not received much attention from researchers until recently (Kane, 2001, 2003). By far the most comprehensive study to develop a measure of quality of life for nursing home residents was conducted by the University of Minnesota for CMS (Kane, 2001, 2003; Kane et al., 2003, 2004). In that study, Kane and colleagues identified 10 quality-of-life domains and developed a survey instrument to measure them. Importantly, facilities appeared to consistently score better or worse across the measurement domains, suggesting that there are "good" and "bad" facilities in terms of quality of life.

Home Health Care

Similar to its Nursing Home Compare website, CMS operates a website that provides quality assessment data on individual home health agencies, Home Health Compare (<http://www.medicare.gov/HHCompare/Home>). This information is designed to help home health patients, their families, and other involved parties (e.g., hospital discharge planners) choose high-quality agencies. It is also designed to provide information to agencies to motivate and guide their quality improvement efforts.

The main source of the home health quality assessment measures on the Home Health Compare website is the Outcome and Assessment Information Set (OASIS). Analogous to the MDS in nursing homes, OASIS is a national standardized data set collected on home health patients that documents key aspects of patients' health status at specified time intervals. OASIS is used both as a quality measurement and to determine Medicare reimbursement levels. The quality measures are based on data collected about home health patients whose care is covered

by Medicare or Medicaid and provided by a Medicare certified home health agency. *Table 3-4* presents the 11 quality indicators that are on the Home Health Compare website.

Table 3-4. Home Health Compare Quality Measures and National Averages

Indicator	National Average (%)
Measures Related to Improvement in Getting Around	
1. Percentage of patients who get better at walking or moving around	41
2. Percentage of patients who get better at getting in and out of bed	53
3. Percentage of patients who have less pain when moving around	63
Measures Related to Meeting the Patient's Activities of Daily Living	
4. Percentage of patients whose bladder control improves	50
5. Percentage of patients who get better at bathing	63
6. Percentage of patients who get better at taking their medicines correctly (by mouth)	41
7. Percentage of patients who are short of breath less often	60
Measures Related to Patient Medical Emergencies	
8. Percentage of patients who had to be admitted to the hospital	28
9. Percentage of patients who need urgent, unplanned medical care	21
Measure About After Home Health Care Ends	
10. Percentage of patients who stay at home after an episode of home health care ends	68

Source: Home Health Compare website, <http://www.medicare.gov/HHCompare>, accessed on 4-9-2007.

As with the Nursing Home Compare website, the Home Health Compare website provides the risk-adjusted percentages of patients meeting the criteria for each measure for the individual facility and, for comparison, includes the state and national averages as well. Unlike the Nursing Home Compare website, inspection data and staffing levels are not available.

The OASIS-based quality measures have most of the same strengths and weaknesses as the nursing home MDS data. The strengths are that the data are based on extensive research and focus on outcomes rather than paperwork or agency policies. The weaknesses are that the data may not be accurate and that statistical issues may limit the ability to differentiate among providers according to quality.

Home and Community-Based Services

The MDS, OASIS, and the survey and certification data system provide a great deal of information about quality of care in nursing homes and home health agencies. However, virtually nothing is known about the quality of home and community-based services, such as personal care, adult day health programs, homemaker services, respite care, assisted living, and adult foster care. Nevertheless, efforts are being made to close this gap, several of which are briefly noted here.

Nonskilled Home Care. Of all modes of long-term care, we know the least about the quality of nonskilled home care services, such as personal care, adult day care, homemaker services, and respite care. Since Medicare does not cover these services and Medicaid and state-funded programs vary dramatically, there are no uniform measures. However, in a study of Medicaid home care beneficiaries in four states, Khatutsky, Anderson, and Wiener (2006) found

the level of consumer satisfaction to be extremely high. Recently, CMS has attempted to give more structure to the quality assurance requirements for Medicaid home and community-based service waivers through the development of a quality matrix and framework for home and community-based services (CMS, 2002b). The range of services, multiplicity of types of providers, and physical dispersion of consumers make data collection more difficult, potentially more expensive, and harder to validate. Some states and researchers have developed mechanisms to measure the quality of home and community-based services (APS Healthcare, Inc., 2003; Dalby, Hirdes, & Fries, 2005; Geron et al., 2000; Wiener & Lutzky, 2001; Wisconsin Department of Health and Family Services, 2001).

Assisted Living and Other Residential Care. In 2004, states reported 36,451 licensed residential care facilities with 937,601 units or beds (Mollica & Johnson-Lamarche, 2005). We know little about the quality of care and quality of life in these assisted living facilities, board and care homes, adult foster homes, and other residential settings for people with disabilities, including compliance with state regulations, staffing patterns, or resident outcomes. States have almost total responsibility for non-nursing home residential care. As a result, there is no standardization across states in terms of definition of various types of residential care, and state regulatory requirements vary greatly (Mollica, 2002). Thus, it is impossible to compare facilities across states (Mollica, 2002; O’Keeffe & Wiener, 2004). Pilot tests have been conducted of a resident assessment instrument for assisted living and adult care homes as part of a study being conducted by Texas A&M Health Sciences Center and the University of Southern Maine. The study will develop quality measures for vulnerable individuals residing in assisted living and residential care facilities (Mollica, 2006).

4. STRATEGIES TO IMPROVE THE QUALITY OF LONG-TERM CARE

To achieve the goals of high-quality long-term care, a large number of strategies have been proposed and implemented. These approaches can be broadly grouped into three categories:

- The first group of strategies is designed to increase mandatory external pressure on providers to improve quality of care. These strategies depend on federal or state government actions setting required standards that providers must meet in order to be licensed or receive government funding. These approaches include strengthening the regulatory process and establishing higher minimum staffing ratios.
- The second group of strategies increases voluntary external incentives on providers to improve quality of care. These strategies depend on federal or state government actions or nonprovider organizations to structure the market in which providers compete for clients or customers. These initiatives include providing consumer information on quality of care, increasing support for consumer advocacy, and changing Medicare and Medicaid reimbursement.
- The third group of strategies includes voluntary approaches by providers to directly change their internal operations. While the federal and state government can facilitate these changes, responsibility for the implementation of these initiatives belongs primarily to providers themselves. These strategies include implementing practice guidelines and changing the organizational culture.

Mandatory Approaches that are External to Providers

Strengthening the Regulatory Process. The main strategy currently used to improve quality of care and quality of life in long-term care in the United States and other countries is direct governmental regulation (Wiener et al., 2007). The regulatory process has three dimensions that interact with program design: (1) discovery: collecting data in order to assess the ongoing implementation of the program; (2) remediation: taking action to remedy specific problems; and (3) continuous improvement: using data and quality information to engage in actions that lead to continuous improvement in program design. The role of government regulation in long-term care varies widely across services, ranging from quite extensive for nursing homes to relatively little oversight of most residential care facilities and home care.

Nursing facilities cannot operate unless they are licensed by the state in which they are located, and they cannot receive Medicare and Medicaid funding unless they are certified as meeting federal quality standards. Inspections must take place on average once every 12 months. Since 78 percent of nursing home residents in 2004 depended on Medicare or Medicaid to finance their care, all but a small number of facilities participate in one or both programs (American Health Care Association, 2007a). Federal standards, survey processes, and enforcement mechanisms overwhelmingly dominate the quality assurance system for nursing facilities.

The Centers for Medicare & Medicaid Services (CMS) relies on the states to administer the regulatory process; CMS's regional offices oversee and monitor the state activities. CMS

establishes specific protocols for state survey teams—generally consisting of registered nurses, social workers, dietitians, and other specialists—to use in conducting surveys. To monitor state compliance with federal rules, CMS performs federal comparative surveys in order to gauge the performance of the state survey systems. These procedures are intended to make on-site surveys thorough and consistent across states. However, the Government Accountability Office (GAO, 2005) found inconsistency in how states conduct surveys and understatement of serious quality problems. For example, California identified actual harm and immediate jeopardy deficiencies in about 6 percent of the state’s nursing homes, while Connecticut found such deficiencies in approximately 54 percent of its facilities. Although possible, it seems unlikely that quality of care actually varies that much across states. Comparing regular survey teams with other teams that surveyed simultaneously within a state, Lee, Gajewski, and Thompson (2006) concluded that the survey process was reliable when assessing aggregate results, but only moderately reliable when examining individual citations.

With regard to the investigation of complaints, enforcement, and oversight, GAO (2005) found that:

- Serious complaints by residents, family members, or staff alleging harm to residents remained uninvestigated for weeks or months, and delays in the reporting of abuse allegations compromised the quality of available evidence, hindering investigations.
- When serious deficiencies were identified, federal and state enforcement policies did not ensure that they were addressed and remained corrected.
- Federal mechanisms for overseeing state monitoring of nursing home quality and safety were limited in their scope and effectiveness.

Much of the recent concern about regulation focuses on enforcement and the predictability of when inspections will take place rather than on nursing home quality standards.

Home health agencies are also licensed by about 40 states. Agencies must meet minimum federal standards to qualify for Medicare and Medicaid funding (GAO, 2003), but states are almost completely responsible for the actual inspections. Neither the states nor the federal government devote many resources to home health inspections and enforcement.

Nonskilled home care is subject to much less regulation than either nursing facilities or home health agencies (Wiener, Tilly & Alexih, 2002; Wiener & Tilly, 2003). Medicaid home and community-based services waivers require states to have a quality assurance plan as part of these programs, but the content of those plans is left up to each state (Smith et al., 2000). CMS assesses state Medicaid quality assurance plans to ensure that states fulfill basic procedures in assuring quality of care for services provided under the waiver. In a review of Medicaid waiver programs for older people, GAO (2003) found that there were quality problems in many of them. No federal requirements apply to Medicaid personal care services that are provided outside of the home and community-based services waivers.

A major new development in home and community-based services is the expansion of consumer-directed home care, where the consumer rather than an agency is responsible for the hiring, scheduling, directing, monitoring, and firing of the worker (Infield, 2005; Wiener, Tilly,

& Alecxih, 2002). CMS is promoting consumer-directed services through the Real Choice Systems Change Grants and the Independence Plus Initiative (O’Keeffe, Wiener, & Greene, 2005). A number of other countries, including the United Kingdom, Germany, and the Netherlands are also promoting this type of care (Wiener, Tilly & Cuellar, 2003).

Compared with agency-directed care, consumer-directed services lack the standard quality assurance structures of required training of paraprofessionals, supervision by professionals, licensing, and inspections. Most states (and countries) have taken fairly minimalist approaches to monitoring quality, relying mostly on complaints and case manager interaction with clients to identify problems (Tilly & Wiener, 2001; Wiener, Tilly, & Cuellar, 2003). In place of formal quality assurance mechanisms, consumer-directed programs rely on the ability of clients to fire unsatisfactory workers and to hire replacements to assure quality—in other words, the market. In addition, a substantial portion of consumer-directed workers are family members or friends, who may be more likely than a stranger to want to provide high-quality care. Despite the lack of regulation, a growing body of research suggests that consumer-directed services are at least as good as agency-directed care and may be better than agency-directed care (Benjamin, Matthias, & Franke, 1998; Foster et al., 2003; Schore, Foster, & Phillips, 2007; Wiener, Anderson & Khatutsky, in press).

States are almost entirely responsible for defining what constitutes an assisted living or residential care facility and for regulating the quality of care provided by them (GAO, 2003). For example, what constitutes an “assisted living facility” varies widely across states, making the term nearly meaningless, and many facilities lack the amenities, services, and philosophy of more comprehensive, high service settings (Hawes, Rose, & Phillips, 2000). Over the last 10 years, a large number of states have enacted licensing requirements for residential care facilities; by 2005, 48 states regulated assisted living facilities (Mollica, 2006).

There is no federal regulation of residential care facilities except under Medicaid home and community-based services waivers. Most residential care facility residents pay privately, but Medicaid and Supplemental Security Income beneficiaries are increasing (O’Keeffe & Wiener, 2004). Although Medicaid does not pay for room and board in residential care facilities, many services offered in assisted living settings are reimbursable through the personal care option or home and community-based services waivers, and the number of Medicaid beneficiaries receiving long-term care services in group residential settings outside of nursing homes increased from 40,000 in 1998 to 121,000 in 2004 (Mollica & Johnson-Lamarche, 2005). In 2004, 42 states and the District of Columbia covered services in residential care facilities under Medicaid, 29 states under home and community-based services waivers, 6 states under the personal care option, and 8 under both options.

Regulation is used cautiously in our free market-oriented economy, yet quality assurance for long-term care is an area dominated by regulation. The rationale for the prominent role of regulation is market failure, such that consumers cannot effectively use their market power to improve quality.

- Many people using long-term care services are severely ill and disabled, and some of these individuals may not have the strength or ability to compare services and facilities. Many people who require long-term care services have cognitive

impairments that make it difficult for them to make quality decisions that are in their long-run interests. Some portion of people using long-term care services have no close family or friends to act on their behalf for their care and protection, if needed.

- Although a great deal of long-term care is nontechnical, many providers serve individuals with substantial health care needs that require medical skills that laypersons are unlikely to be able to evaluate.
- High occupancy rates in nursing homes and shortage of home and community-based services providers may mean that providers are able to operate at near capacity without having to compete based on quality of care. This may be especially true of providers focusing on Medicaid beneficiaries.
- Decisions about the appropriate type of care and a quality provider are often made more difficult by the need to make decisions during a very brief time period while under substantial stress.
- Nursing homes and other residential settings, in particular, are “total institutions” where individuals live 24 hours a day. Fear of physical abuse and other retribution from staff may prevent residents from complaining, and difficulty finding other placements may prevent them from leaving.

Enforcing regulations is a classic policing function in which providers who do not meet the regulatory requirements are identified and punished. Consumer advocates claim that an arms-length relationship between the regulators and facilities is critical to the effectiveness of this approach, but providers argue for a more consultative approach (Edelman, 2001).

However, regulation carries disadvantages. While ideally, regulation would focus on quality of life and on quality of care, it sometimes focuses on structural characteristics, such as the physical plant, whether procedures codified, and whether activities are documented. This creates several difficulties:

- It can be very difficult to specify inputs and procedures that are not subject to gaming by providers.
- Long-term care regulations largely set “floors,” possibly encouraging providers to “satisfice” rather than to provide high-quality care.
- The framework relating inputs to quality may be incomplete or inaccurate, leading to inappropriate regulations.
- Changes in society, technology, and other factors may subsequently change the relationships between specific inputs and quality of care and life. As a result, regulation may hinder innovation (Institute of Medicine 2001a).

Advocates of government regulation argue that enforcement remains too weak and that stronger regulation would greatly improve quality of care. Most recommendations by consumer advocates and GAO (2003; 2007) for strengthening the regulatory process involve more aggressive enforcement of existing regulations. This approach could be initiated by the federal government, but state governments could take the lead, if they so choose. For example, for nursing homes this would include:

- targeting chronically poor-performing facilities and working to change ownership or put them out of business;
- strengthening the severity rating of deficiencies to define more situations as serious;
- increasing training of surveyors;
- reducing the predictability of the timing of the survey;
- shortening the length of time for investigating complaints that allege actual harm to residents;
- imposing more fines and other penalties, especially for facilities that place residents in immediate jeopardy; and
- strengthening and making more consistent the federal oversight of state survey activities.

Federal spending for survey and certification totaled \$258 million in FY2006 (U.S. Office of Management and Budget, 2007). Advocates for more aggressive regulation argue that additional funding would provide the resources needed to more actively monitor and enforce federal regulations. Increased regulatory review has the potential to provide a more complete and accurate determination of good versus underperforming facilities, although research suggests that the observation of care provided to residents in and of itself is unlikely to change provider behavior (Schnelle, Ouslander, & Simmons, 2006). Medicare survey and certification expenses are predominantly funded at the federal level, with the federal government funding 100 percent of the costs associated with certifying that nursing homes meet Medicare requirements and 75 percent of the costs associated with Medicaid standards (GAO, 2005). The states are responsible for the remaining 25 percent of the Medicaid portion of these surveys. State budget problems have caused hiring freezes and resistance to increasing staff in survey agencies (Scully, 2003).

On the other hand, critics of federal and state regulation argue that the current regulatory system has numerous deficiencies, such as the following:

- Critics believe that nursing facility regulations are not evidence based and do not measure what is important. Despite OBRA '87, federal and state regulations still emphasize inputs, manuals, paperwork, and structural capacity rather than resident outcomes. Moreover, they blame much of the poor quality of life in nursing facilities on rigid regulations, which force a “medical model” on nursing homes.
- Opponents of stricter regulation also argue that detailed rules stifle innovation, with few incentives for doing more than the minimum. The dilemma is how to give good-quality facilities more flexibility, while still requiring substandard facilities to meet adequate standards.
- Providers complain that the current regulatory environment has “poisoned” the relationships between nursing homes and state surveyors in ways that are not productive. Moreover, they contend that the unrelentingly negative view of nursing homes in the media has made it extremely difficult to recruit and retain high-quality staff.

- Many proposals for improving the regulatory system require substantially more financial resources for gathering information and for surveying facilities and enforcing sanctions. Lack of funding for nursing facility quality assurance at both the federal and state levels has been a chronic problem.
- While regulatory sanctions are meant to punish the owners or administrators of poor-quality nursing facilities, it is hard to avoid “punishing” the residents at the same time. For example, decertifying a facility may require the relocation of a large number of residents, which is hard to achieve because of relatively high nursing home occupancy rates, and which will cause disruption to residents’ lives and social relations. Likewise, “intermediate sanctions,” such as freezing admissions of new Medicare or Medicaid beneficiaries or imposing civil money penalties, will result in reduced cash payments to facilities that may need to be spending more money on staff and other services. This inability to separate nursing homes from their residents is a major constraint on the willingness of regulators to impose tough sanctions on poor-quality facilities.

In response to the problems of government regulation, the nursing home industry and some other providers have proposed that the inspection function be transferred from government to private accrediting bodies, such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), usually at the option of the provider. In the case of hospitals and home health agencies, the provider organization does not have to undergo a separate government survey; instead, CMS relies on the accrediting body’s evaluation to make its Medicare or Medicaid certification or licensure decision. This so-called “deemed status” option has existed for hospitals since the beginning of the Medicare program.

Consumer groups involved in nursing home care have strongly opposed deemed status and have criticized the rigor of the inspection process of accrediting bodies. In the current system, providers pay the accrediting body for the service, creating a potential conflict of interest. In addition, a study by Abt Associates concluded that the private survey inspections of nursing homes done by JCAHO were not effective in protecting the health and safety of nursing home residents (Health Care Financing Administration [HCFA], 1998). For example, in a sample comparing government and JCAHO inspections of the same nursing facilities, JCAHO failed to detect half of the serious problems identified by HCFA. All parties agree, however, that accreditation can play a role in encouraging providers to go beyond the basic governmental regulations and strive toward higher standards (Institute of Medicine, 2001a).

Strengthening the Caregiving Workforce. Although technology is important and its role is likely to increase, long-term care is overwhelmingly a service that is provided by people, not machines. In the current system, it is often alleged that quality is impaired because staffing is inadequate in nursing homes; staff are insufficiently trained, and staff turnover is high, especially for certified nurse assistants (Stone & Wiener, 2001; Decker et al., 2003). Three approaches have been proposed to improve the quality of long-term care by strengthening the caregiving workforce:

- Increase the number of personnel in nursing homes by mandating higher and more specific minimum staffing ratios.

- Increase the required minimum training of people who work in all of long-term care, especially certified nurse assistants who work in nursing homes.
- Improve wages, benefits, and working conditions in long-term care to attract and retain “better,” more qualified staff.

Staffing ratios. Federal standards for staffing in nursing homes do not specify particular minimum quantities of staff per resident. Although OBRA ‘87 requires that nursing facilities have licensed nurses on duty 24 hours a day, a registered nurse (RN) on duty at least 8 hours a day, 7 days a week, and an RN Director of Nursing, these requirements are not adjusted for facility size, number of residents, or case mix. Instead, the law requires that the facility have “sufficient” staff to provide nursing and related services to attain or maintain the “highest practicable level” of physical, mental, and psychosocial well-being of every resident. Neither federal law nor regulation provides specific guidance as to what constitutes “sufficient” staffing. Many states have minimum staffing requirements for nursing facilities, and some have minimum staffing requirements for assisted living facilities.

The number of personnel per resident varies widely across facilities. For example, in 1998, the median facility provided 3.21 hours per day of nursing time, but the 10th percentile facility provided only 2.46 hours per day, and the 90th percentile facility provided 4.66 hours per day (Harrington & Carillo, 2000). A CMS report to Congress concluded that the overwhelming majority of nursing facilities were understaffed (HCFA, 2000). Overall nursing facility staffing increased slightly between 2000 and 2006 due to an increase in certified nurse assistant and licensed practical nursing hours, but staffing of registered nurses declined slightly (American Health Care Association, 2006).

A number of studies have found a positive association between nurse staffing levels (especially for RNs) and the processes and outcomes of care in nursing homes (Institute of Medicine, 1996, 2001a). For example, Harrington et al. (2000b) showed that higher nurse staffing hours were associated with fewer nursing home deficiencies. Many reports of poor-quality care (e.g., rushed feeding and not answering call bells) appear to be linked to inadequate staffing levels. In a review of the literature, Bostick et al. (2006) concluded that there is an association between higher total staffing levels (especially licensed staff) and improved quality of care, and a relationship between high turnover and poor resident outcomes. Pointing up the inadequate levels of attention received by some residents, Port (2006) found that illness detection among cognitively impaired nursing home residents was positively correlated with the level of informal rather than formal caregiver involvement.

Many clinicians, researchers, and consumer advocates consider the federal nursing home staffing standards to be vague and have called for higher, more specific standards. Thus, one option would be to establish federal minimum staffing standards for nursing facilities. For example, nursing facility staffing could be set at the standards proposed by the National Citizen’s Coalition for Nursing Home Reform, a panel of experts led by Charlene Harrington, a nursing home expert at the University of California–San Francisco, or the CMS report to Congress. States, at their discretion, could also implement these standards through their licensure requirements. Based on expert opinion, the National Citizens’ Coalition for Nursing Home Reform (1995) and the Harrington panel (Harrington et al., 2000a) have recommended minimum staffing at the 80th to 90th percentile of current staffing in nursing facilities (Institute of

Medicine, 2001a). The CMS report to Congress (CMS, 2002a) found “strong and compelling” statistical evidence that nursing homes with a low ratio of nursing personnel to patients were more likely to provide substandard care, and the study authors recommended a *minimum* staffing ratio of 4.1 hours of care per day, about 20 percent higher than *average* current staff levels.

The nursing home industry and many government officials oppose the imposition of higher and more specific staffing requirements. They argue:

- *How staff are organized, supervised, and motivated is at least as important as the number of workers.* Merely “throwing bodies” into a poorly run facility, they contend, will not improve quality of care.
- *A major difficulty in setting standards is that there is little empirical, quantitative research on what the minimal staffing level should be.* All proposals for increased staffing, except for the CMS study, rely solely on expert opinion and fail to adjust for case mix, which is the primary determinant of staffing needs.
- *Depending on the minimum staffing level established, the additional costs could be significant.* A preliminary analysis by CMS’s Office of the Actuary estimated that increasing nursing home staffing to the recommended 4.1 hours per day per nursing home resident would increase total nursing home costs by \$7.6 billion, or 8.4 percent, in 2001 (CMS, 2001). Medicaid would incur perhaps two thirds of these costs.
- *The shortage of staff to work in long-term care makes higher staffing levels unrealistic.* Recruiting and retaining workers is difficult (Decker et al., 2003). Thus, even with the best of intentions, it may be difficult to increase staffing levels.

Staff training. One possible reason for poor quality in long-term care is that staff are not adequately trained. Especially with the increased acuity of nursing home residents and the greater complexity of care provided today, one strategy to improve quality of care is to significantly increase training requirements for all types of long-term care staff, especially those in nursing homes. For example, a quality improvement initiative for chronic pain assessment and management was associated with improvement in documentation and in the level of satisfaction for residents and families (Buhr & White, 2006). For nursing homes and home health agencies participating in Medicare and Medicaid, the federal government could set higher minimum standards. States, at their discretion, could impose higher standards for these providers as well as for nonskilled home care and assisted living facilities.

Certified nurse assistants and home health aides provide most of the direct care in nursing homes and home health agencies, but they receive little formal training. OBRA ‘87 requires nursing assistants to receive a minimum of 75 hours of entry-level training, to participate in 12 hours of in-service training per year, and to pass a competency exam within 4 months of employment. Some states, such as California, require longer periods of training. Similar federal requirements exist for home health aides. While most states have entry-level training requirements for home care workers and some level of criminal background check to identify potentially abusive staff, not all states do, and most training requirements are minimal (Institute of Medicine, 2001a). As nominal as the training requirements are, they exceed what most other

low-paid jobs require and may deter some people from working in the industry. On the other hand, the minimal training also means that there is no career ladder for this type of work; it is the classic “dead-end job.”

There are three major issues involving staff training requirements:

- *Although there is a logic to formal minimum training requirements, little research has been done to determine what those levels should be and what impact increased training has on quality of care.*
- *Training is not free. The costs of higher standards must be borne by workers, facilities, or the government.*
- *Higher training requirements may exacerbate the staffing shortage by creating barriers to entry to working in long-term care.*

While quality initiatives focus on paid providers, the vast majority of long-term care is provided by informal, unpaid caregivers (Arno, Levine, & Memmott, 1999; Liu, Manton, & Aragon, 2000; Johnson & Wiener, 2007). One study estimated that 18.7 billion hours of informal personal assistance services were provided to adults living in the community in 1996 (LaPlante, Harrington, & Taewoon, 2002).

Despite the critical role played by informal caregivers, training programs to help family members care for their disabled relatives are not common. As a result, family members may not have critical skills, such as the best way to lift a disabled person, or understand the course of an illness, such as Alzheimer’s disease. The National Family Caregiver Support Program, established by the Older Americans Act Amendments of 2000, is probably the main funder of federal government efforts to provide caregiver training. Budgeted at roughly \$150 million per year in recent years, the program provides caregiver training in addition to information, counseling, respite care, and some limited supplemental services. Another source of funding for caregiver training programs is the Alzheimer’s Disease Demonstration Grants to States program, also administered by the Administration on Aging, which funded demonstration grants in 38 state government agencies in 2006. There are also a number of other smaller projects and demonstrations that attempt to fill some of this training gap (Administration on Aging, 2004; Link et al., 2006; Robert Wood Johnson Foundation, 2002). And some private long-term care insurance policies will pay for informal caregiver training, including the Federal Long Term-Care Insurance Program. One possible quality initiative would be to increase the funding for training of informal caregivers.

Wages and benefits. Although cyclical economic conditions significantly affect demand for paraprofessional workers, low wages and lack of benefits along with difficult working conditions make recruitment and retention of nursing aides difficult, even when unemployment rates are high (Stone & Wiener, 2001). As a result, some providers are understaffed, and the constant turnover adversely affects the ability of staff to understand the needs and preferences of individual clients and to develop a personal rapport with them. Difficulty in recruiting aides is likely to worsen over time as the number of people needing long-term care increases more quickly than the working-age population.

Long-term care workers, such as personal care attendants, certified nurse assistants, and home health aides, receive low wages and generally lack fringe benefits such as health insurance and pension plans (Cousineau, Regan, & Kokkinis, 2000; Crown, Ahlburg, & MacAdam, 1995; Yamada, 2002). For example, median earnings of personal and home care aides were \$8.12 per hour in 2004 (U.S. Bureau of Labor Statistics, 2006). Because care is often needed only at the beginning and end of the day in connection with getting in and out of bed, many home care aides can only work part-time, further reducing their earnings. Vacation and sick leave are also often not available.

Standard economic theory predicts that higher real wages and benefits would help draw more workers into the long-term care sector, resulting in higher staffing and increased continuity of care. The mobility of the labor supply across occupations with few education and training requirements is relatively high (Ehrenberg & Smith, 1997), and the number of workers who might be available for such shifts is substantial. Providing higher wages and benefits could also provide a better life for workers.

To implement higher wages and benefits, the federal government would need to increase Medicare reimbursement rates for nursing facilities and home health agencies, and state governments would need to raise Medicaid and state-funded programs' reimbursement rates for nursing home and other services. In the late 1990s, several states passed wage pass-throughs in their Medicaid reimbursement rates for nursing homes, requiring that higher payments be passed on to workers as wage and benefit increases, a practice that was abandoned due to fiscal crises at the state level during the early 2000s (Stone & Wiener, 2001).

Although not insurmountable, raising wages and benefits face three difficulties:

- *Because of the heavy dependence of long-term care on public financing, especially Medicaid, raising wages will mean increases in government expenditures.*
- *Verifying that reimbursement increases result in wage and benefit increases is not always easy, although increased regulatory oversight could reduce this problem.* Tracking facility expenditures would require additional data from providers that some would view as burdensome.
- *Although consistent with economic theory, there is limited research on the effects of higher wages and fringe benefits on recruitment and retention or on quality of care* (Harris-Kojetin et al., 2004). In one of the few studies of this topic, Howes (2002) found that a very large increase in wages for personal care workers in San Francisco County, California, significantly reduced staff turnover. However, other concurrent events that would be expected also to reduce turnover could not be controlled for and the impact of smaller increases are not known. Thus, although there is a strong logic in favor of increased wages, policymakers may not have confidence that the impact of higher wages will be worth the cost.

Voluntary Approaches that are External to Providers

Providing Consumers with More Information and Options. One increasingly prominent approach to improving quality of care is to provide more information to consumers, their families, providers, hospital discharge planners, and others about the quality of individual long-term care providers (Harrington et al., 2003; Mukamel & Spector, 2003). The underlying premise is that the lack of information on quality results in a market failure. The premise of this approach is that armed with more information about quality of care, consumers will choose high-quality providers and avoid poor-quality providers (Bishop, 1988). Thus, in theory, market competition for residents and clients would force poor-performing providers to improve their quality of care or go out of business. Hospital discharge planners, case managers, and others involved in the placement process could also use the information to advise individuals needing services and their families. Providers could also use the information to identify areas for improvement.

CMS has embraced this approach as a key component of its quality improvement strategy for a number of providers, including nursing homes, home health agencies, and end-stage renal disease dialysis facilities. The CMS Nursing Home Quality Initiative and Home Health Quality Initiative are built around this approach. Since 1998, CMS has operated the Nursing Home Compare website that provides a wide variety of quality-related information about individual nursing homes (CMS, 2004b). This website has been popular, averaging approximately 100,000 visits per month (U.S. House of Representatives, Committee on Government Reform, 2002). In addition, there are websites that report quality information on individual nursing homes in California, Florida, Iowa, Maryland, Ohio, and Virginia (Shugarman & Garland, 2006).

Recognizing that a nursing home placement decision often involves family members in addition to the prospective resident, and that some residents may have some degree of cognitive impairment, Maryland sponsored a Nursing Home Family Satisfaction Survey, which assessed the views of the “responsible party” for nursing home residents (most often a son, daughter, or spouse). The pilot survey found that the highest rated satisfaction domains statewide were Staff and Administration and Physical Environment of the nursing home, while the two lowest rated domains were Food and Meals and Activities available to residents. They also found that smaller facility size was associated with higher satisfaction ratings, and that nonprofit facilities scored higher on all overall satisfaction measures and domain measures compared to for-profit facilities (Maryland Health Care Commission, 2006).

Building on the Nursing Home Quality Initiative, CMS launched the Home Health Compare website, after developing quality indicators for home health agencies from OASIS data on individual patients (CMS, 2004a).

Whatever quality information is available on assisted living is provided at the state or local level. Mollica (2006) found that 46 states provide access to a database or list of licensed facilities, 12 states post survey findings on their website, and 14 states post a guide to help consumers learn about and choose a facility. In addition, 26 State Units on Aging post information about assisted living on their websites.

One strategy for improving quality of care in long-term care would be to more actively publicize the availability of the federal and state quality-of-care data on nursing homes and home

health agencies. A further option would be to develop similar public reporting data for assisted living facilities and other home and community-based services. To do so, substantial new data would have to be collected and research conducted to establish the validity and reliability of quality measures.

Although there is widespread support for providing more information to consumers, the research literature on consumer response to quality of care information in health care is mixed, but mildly positive (Barr et al., 2002; Chernew & Scanlon, 1998; Hibbard, Stockard, & Tusler, 2002; Knutson et al., 1998; McCormack et al., 2001; Short et al., 2002; Vaiana & McGlynn, 2002). And while Nursing Home Compare has received substantial publicity and is well known among policy analysts, its reach into the population at large is more limited. A recent study using focus groups found that few consumers used the Internet to obtain information for an impending nursing home placement, and few participants in the focus groups were aware of Nursing Home Compare (Shugarman & Brown, 2006). Moreover, Stevenson (2006) found that the impact of Nursing Home Compare on occupancy rates for facilities with high- and low-quality rankings was minimal.

Several factors may make consumer information on nursing homes and home health agencies less effective in influencing consumer choice than information for other health care, such as managed care or health insurance plans:

- *The ability of information to guide decisions is only as good as the information provided.* Some observers contend that MDS and OASIS data may be inaccurate since they are filled out by providers. Since CMS uses these data to sanction facilities and agencies, staff have strong incentives to provide data that avoid these negative sanctions. At least one study, however, found good levels of reliability in MDS-derived quality indicators (Morris et al., 2002).
- *There may be structural problems in the nursing home and home health market that limit competition based on quality.* For example, although nursing facility occupancy rates have fallen somewhat, they are still relatively high in many parts of the country and increased slightly between 2000 and 2006, potentially limiting consumer choice of providers (American Health Care Association, 2006). High demand, which results in high nursing facility occupancy rates, may also reduce the desire of facilities to compete based on quality since they can fill their beds at lower-quality levels (Cohen & Spector, 1996; Grabowski, 2001; Nyman, 1985). High occupancy rates especially may limit competition for Medicaid nursing facility residents, for whom reimbursement is lower than for private pay residents.
- *Characteristics of the nursing home and home health placement process may make use of consumer information difficult.* Many nursing home and home health decisions are made on an urgent basis, and consumers may not have the time to thoroughly research a variety of nursing homes and home health agencies. Individual consumers are usually quite sick, disabled, or cognitively impaired, making it hard for them to be active consumers; friends and relatives often act as decision makers in their place. Placements in nursing homes, in particular, often involve a great deal of family stress and emotion (Shugarman & Brown, 2006). Moreover, conventional wisdom holds that searches for nursing homes and home

health agencies are typically made in very small geographic areas, limiting the number of possible provider choices (Mukamel & Spector, 2003). In some areas, especially rural communities, there may be only one provider, making quality of care data less compelling to consumers because there are no alternatives. In addition, quality is multidimensional, and research on nursing homes surprisingly suggests that quality of care is not highly correlated across care domains (Mukamel & Brower, 1998; Mukamel & Spector, 2002; Porell & Caro, 1998). Thus, some facilities and agencies may rate highly on some dimensions of care but poorly on others.

- *Outreach efforts may be needed to ensure that all who need consumer information are effectively reached.* A major challenge for CMS is to provide information to ethnic and minority groups for whom language and access to the Internet may be barriers. For example, in 2002, 2.0 million older people (aged 65 or older) in the United States were Hispanic/Latino, 5.5 percent of the older population; by 2050, 13.4 million older people in the United States are projected to be Hispanic/Latino, 16 percent of the older population (Administration on Aging, n.d.). Aside from the language barrier, reaching the Hispanic/Latino population is both difficult and important because they are considerably less educated, poorer, have less access to medical care, and are more disabled than non-Hispanic whites.

Strengthening Consumer Advocacy. Consumer advocacy programs perform a range of functions, including assisting with individual complaints and mediating conflicts, advocating public policies to improve quality of care, educating the public about quality of care and consumer protection, and raising the public policy salience of quality issues. In perhaps their most notable achievement, consumer activists spearheaded the passage of the Nursing Home Reform Act in OBRA '87. Strengthening consumer advocacy groups involved with long-term care quality issues would be a way of changing the balance of power among stakeholders, helping to ensure continuing attention to the issue, and providing political support for quality initiatives. Some countries, including the Netherlands, provide funding to consumer groups to represent their interests in policy debates (Wiener, Tilly & Cuellar, 2003). Private foundations could provide support for these organizations, and the federal government could provide higher funding for the Administration on Aging's Long-Term Care Ombudsman program.

A number of groups represent consumers on quality of care in long-term care, especially nursing home residents. The Long-Term Care Ombudsman program, created by the Older Americans Act, is the largest program devoted to the interests of consumers at both the individual and system levels. Long-term care ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. Long-term care ombudsmen advocate on behalf of individuals and groups of residents, provide information to residents and their families about the long-term care system, and work to effect systems changes at the local, state, and national levels. They provide an ongoing presence in long-term care facilities, monitoring care and conditions and providing a voice for residents. The Ombudsman program is usually operated by the State Unit on Aging. About 1,000 paid and 14,000 volunteer staff (8,000 certified) investigate over 260,000 complaints each year. They provide information to more than 280,000 people on myriad topics, including how to select and pay for a long-term care facility (Administration on Aging, 2007). In FY2005, Congress appropriated \$14.2 million for this program. In the view of some observers, the program has

been underfunded (Institute of Medicine, 1995). OBRA '87 also provides for the right of residents and family members to organize resident councils in nursing facilities.

In addition, a variety of independent advocacy groups, including the National Citizens' Coalition for Nursing Home Reform, the Center for Advocacy for the Rights and Interests of the Elderly, the California Advocates for Nursing Home Reform, the Center for Medicare Advocacy, and the National Senior Citizens Law Center, have been active in issues of nursing home quality. Some groups representing younger people with disabilities, such as ADAPT, have made long-term care a central focus of their activities. Of course, a wide range of consumer groups representing older people, such as AARP and the National Council on the Aging, have an interest in quality of long-term care, among other topics, but it has not been a central focus. Few groups address quality issues in home and community-based services.

Consumer advocacy, however, faces major structural limitations. These include:

- *Consumer groups at the state and local levels are often limited by their reliance on volunteers, for whom advocacy is not their main occupation. As a result, simply attending meetings and public hearings can be difficult because they are usually held during the workday when volunteers are at their paying jobs.*
- *Local advocacy groups often lack the technical expertise needed to translate broad values and goals into specific recommendations for policy, regulatory, and legislative changes. Volunteers often do not know the details of regulations or funding requirements.*
- *In terms of consumer advocacy on behalf of specific individuals, fear of retaliation against residents by nursing home or other provider staff may keep residents and their families from protesting poor conditions (Institute of Medicine, 1995). Arguably, this is more important in nursing homes and other residential settings, where the resident lives 24 hours a day.*

Increasing and Restructuring Medicare and Medicaid Reimbursement. Compared to acute care services, long-term care is much more heavily dependent on public sources of reimbursement (U.S. Congressional Budget Office, 2004a). Thus, the reimbursement policies of Medicare and Medicaid are critical to the level of resources available to long-term care providers, and to the extent that more resources translate into better quality, public reimbursement is a key factor. In addition, the form and type of reimbursement can provide incentives or disincentives for high quality.

Medicaid and Medicare long-term care reimbursement policy is particularly important as a policy lever because federal and state policymakers have great control over both the level and methodology of payment. The federal government sets Medicare reimbursement policy, and states have almost complete freedom in setting Medicaid long-term care payment rates (Wiener & Stevenson, 1998). Providers often argue for increased Medicare and Medicaid reimbursement rates as a way to improve quality of care, arguing that resources provided by public reimbursement are inadequate. BDO Seidman (2006), in a study for the American Health Care Association, estimated that unreimbursed nursing home Medicaid allowable costs were \$4.5 billion in 2006. An important feature of the long-term care market is that private payment rates are almost always higher than Medicaid reimbursement levels.

Not only is the level of payment important, but so is the method of payment. Payment for a range of services under Medicare has shifted from retrospective, cost basis reimbursement to prospective payment. Payment levels vary according to selected characteristics of the individual, and a few selected characteristics of the provider, but not according to the actual costs incurred by each provider for treating each individual. Medicare pays prospectively for skilled nursing facility and home health care, as do almost all Medicaid agencies for nursing home care.

Since prospective payment systems typically allow providers to keep the difference between the payment rate and the cost of providing services, it may provide incentives for providers to reduce costs related to patient care, which may adversely affect quality. White (2005) analyzed the effects of the shift to Medicare prospective payment (from 1997 to 2001) for skilled nursing facilities on staffing and selected measures of quality of care. He found a positive but small association between changes in payment levels and changes in nurse staffing. But among for-profit skilled nursing facilities, the switch to prospective reimbursement was associated with a large drop in nurse staffing. White also found that this switch in payment method was associated with a worsening in one of the four measures of quality of care he examined. However, this latter association was not statistically robust.

There are two additional issues with raising Medicare and Medicaid reimbursement rates as a strategy of improving quality of care in long-term care:

- *The relationship between reimbursement levels and quality of care is not simple, and it is not certain that higher reimbursement rates will improve quality of care.* Although research in this area is limited, some older nursing home studies have found that higher reimbursement is associated with more staffing but have failed to find a significant relationship to other measures of quality (Cohen & Spector, 1996; Nyman, 1988). In contrast, more recent studies have found a relationship between costs and quality outcomes in nursing homes, although the effect size is relatively small (Grabowski, 2004; Grabowski & Angelelli, 2004; Grabowski, Angelelli, & Mor, 2004). That is, relatively large increases in reimbursement are associated with relatively small improvements in quality of care.
- *Higher Medicare and Medicaid reimbursement levels add to public costs.* Thus, the dilemma for policymakers is that a dollar's worth of increased reimbursement does not yield a dollar's worth of quality improvement. Higher rates are diluted in a number of ways—including higher administrative expenses, profits, inefficiency, and sometimes fraud—that do not improve resident outcomes.

Incorporating Quality Incentives into Reimbursement. The most recent innovation in paying for health and long-term care is “pay for performance” (or P4P), the name given to integrating quality incentives directly into the reimbursement mechanism. Prospective payment systems control spending better than cost-based reimbursement, and they create incentives to reduce costs because payments do not decrease when a provider's costs decrease. However, prospective payment systems may contain incentives that can conflict with improving the quality of care. For example, if a provider spends an additional dollar to improve quality, payments will not increase as a result. This means that quality improvement efforts that increase costs must come out of profits or operating surplus.

An ideal reimbursement system will incorporate both incentives to economize on costs and incentives to maintain and improve quality. This is the promise of pay for performance—combining some type of fixed prospective payment with incentive payments that vary according to measures of the quality of the care provided. To explore this concept, CMS has started a number of pay-for-performance initiatives (CMS, 2005). These demonstrations largely focus on health care rather than long-term care delivered under Medicare, but some deal with persons dually eligible for Medicare and Medicaid or on chronic care (CMS, 2007).

The most likely initial application of pay for performance in long-term care would appear to be for nursing facility care. A few state Medicaid programs, including Massachusetts, provided small financial payments above the normal rate in the past to high-quality providers. An outcomes-based reimbursement demonstration implemented in 36 proprietary nursing facilities in the San Diego area from 1980 to 1983 found beneficial effects on access, quality, and cost of care (Norton, 1992; Weissert et al., 1983), but it took place over 25 years ago.

CMS has funded a design effort in anticipation of a multistate demonstration of a Medicare skilled nursing facility quality-based purchasing system. This design effort (White et al., 2006) concluded that such a system should have the following characteristics:

- *Performance measures.* The system should include four categories of performance measures: (1) nursing home staffing level and turnover, (2) rate of potentially avoidable hospitalizations, (3) MDS-based resident outcome measures, and (4) outcomes from state survey inspections.
- *Linking nursing home performance to performance payments.* Homes with overall performance scores that are in the top 20 percent of performance levels should qualify for a performance payment. Homes in the top 20 percent in terms of improvement should qualify for a performance payment in recognition of their better performance, so long as their performance is at least in the 40th percentile in the performance year. Under the demonstration no homes will face payment reductions as a result of poor performance.
- *The size of the performance payment pool.* The size of the payment pool should be based on whether the demonstration results in savings to the Medicare program. If there are no savings, then there would be no performance payments regardless of any quality improvements.

Some states are also exploring ways to link Medicaid payments to quality. In response to a legislative mandate, the state of Minnesota devised a system that would affect all nursing home residents in the state (Kane et al., 2007). The quality score to be used in this system would be a weighted composite of a number of measures, including several calculated from the MDS, as well as a measure of quality of life and consumer satisfaction derived from a survey of a sample of nursing home residents. In spite of the desire to focus on quality outcomes, the score also incorporates several structural and facility process measures, including staffing level, turnover, and retention. Payment would be based on a facility's quality score and its costs. After case-mix and regional wage rate adjustments, facilities that provide higher-quality care at lower cost would receive payments in excess of their costs, whereas facilities that provide lower-quality care at higher cost would receive payments below their costs.

The implementation of this payment system has been postponed indefinitely, largely due to concerns of the Minnesota nursing home industry. However, in its place, a portion of the cost-of-living adjustment for nursing home payments was diverted to a quality-based add-on, the amount of which is determined as a function of the quality measures contained in the Minnesota Nursing Home Report Card (<http://www.health.state.mn.us/nhreportcard>).

Critics point out several problems with the pay-for-performance approach:

- *There are substantial technical problems related to establishing unambiguous measures of “high” quality.* There is a risk that facilities providing average or even low quality may qualify for financial incentives.
- *Quality incentive payments may “guild the lily” by providing additional funds to facilities that already are likely to be doing well financially because they may have a high percentage of private pay residents who pay charges greater than Medicaid.* Thus, there is the issue of providing additional funds to providers who do not need any more resources, inefficiently using public resources.

Voluntary Strategies that are Internal to Providers

While the previous strategies rely on forces outside of long-term care providers to either force agencies or facilities to improve quality of care or to provide incentives for them to do so, a strong argument can be made that providers themselves must assume responsibility to improve quality of care. In this view, providers must take responsibility for changes at the micro level where individual caregivers interact with individual long-term care consumers.

Developing and Implementing Practice Guidelines. To help providers provide better technical care, practice protocols have been developed for a number of conditions, including incontinence, restraints, pressure ulcers, pain, and depression. These guidelines aim to bridge the gap between the clinical research literature and providers, often using algorithms to guide assessment and treatment (Institute of Medicine, 2001a). The fact that most long-term care involves relatively low-tech services arguably ought to make these protocols easier to develop and to implement. Thus, quality of care might be improved by developing more protocols and encouraging nursing homes, home health, home care, and assisted living facilities to use them. To date, these protocols have not addressed quality-of-life issues, and it is not clear that those factors, which largely embody staff attitudes, can be reduced to practice protocols.

One option for reform would be for federal and state governments, foundations, and provider associations to fund research on practice protocols and to more actively disseminate practice guidelines by providing training and copies of the protocols. So far, however, there is little evidence that guidelines are routinely or effectively implemented in nursing homes, or even that existing guidelines are widely known by direct-care nursing home staff (Colon-Emeric et al., 2006; Institute of Medicine, 2001a; Schnelle, Ouslander, & Cruise, 1997). Even when research protocols have been successfully implemented and shown to be effective, they may not be continued after the sponsoring project ends (Schnelle, Ouslander & Cruise, 1997).

There are several major barriers to the use of protocols:

- *Practice guidelines often require more, not less, staff, who are typically not available in nursing homes* (Beck et al., 1997; Rogers et al., 1999). In a study of the implementation of an effective incontinence and exercise protocol that reduced wetness and improved ambulation, Schnelle and colleagues (1998) found that the new procedures required four to six times as much time for these tasks as staff normally provided.
- *To the extent that protocols address care that is monitored in regulatory standards and measure performance against those standards, providers often prefer to record unsubstantiated compliance rather than risk sanctions from surveyors by documenting less than perfect performance.* In a study of physical restraint protocols, Schnelle, Ouslander, and Cruise (1997) reported that despite demonstrated improved performance from a new low-cost procedure, the participating nursing homes abandoned the new process after the research project ended. A major reason for doing so was that surveyors accepted paper compliance recorded in the record as meeting the care standards, even though it was inaccurate.

Changing the Organizational Culture of Long-Term Care Providers. Some observers have argued that the quality problems in long-term care are a result of an organizational culture that is too hierarchical, too medical, and too bureaucratic. In response, especially for nursing home care, a number of new approaches to structuring the social, cultural, and physical environments of the facilities have developed. The so-called “Eden Alternative” is probably the best known of these innovations in the nursing home sector (Thomas, 1994). This approach emphasizes community by linking the facility to the outside world—plants and animals are allowed, children interact with residents, and aides are empowered as an essential part of the care team. Many of these models involve physically redesigning the facility, emphasizing small “neighborhood” communities, and changing staffing patterns to promote continuity of care. This approach has led to the “Green House” movement, a particular embodiment of culture change for nursing homes that involves small facilities that are very homelike and where certified nursing assistants are deeply involved in decision-making (Rabig et al., 2006). Denmark has reformed its nursing homes along these lines (Stuart & Weinrich, 2001).

These innovations are intuitively appealing and appear to address many of the quality-of-life problems in traditional nursing homes. Encouraging these new care models by publicizing them and by providing implementation grants from federal and state governments and foundations might improve quality of care and life. In addition, federal and state regulations that hinder demonstrations could be modified.

While intriguing, these innovative programs are relatively recent and rare. At least five issues confront advocates of using these models for quality improvement:

- *Although there has been a lot of media coverage, these innovations have not been rigorously evaluated or replicated under varying leadership, ownership, and case mix circumstances.* In particular, some of the most dramatic changes may be the

result of charismatic leadership, which may not be replicable when implemented on a broader scale.

- *Implementing some of these models can be difficult because they are inconsistent with existing regulations.* For example, the presence of birds or animals may violate sanitation requirements, and some of the staffing arrangements skirt the boundaries of regulatory acceptability. Given that a number of facilities have implemented these changes, however, these barriers do not appear to be insurmountable.
- *As the population in nursing facilities becomes more disabled and involves higher levels of medical complexity, some of the more medical characteristics of nursing facilities may be more appropriate than they were in the past and may be compromised by these new approaches.* The average nursing home resident has 3.96 problems with activities of daily living (American Health Care Association, 2007b).
- *As with the care protocols discussed above, these approaches may end up requiring more staff and higher costs.*
- *There are approximately 16,000 nursing facilities in the United States, making it difficult to design initiatives that will result in radical cultural change beyond a handful of facilities.* Especially from a policy perspective, it is not clear how to change the culture of a large number of nursing homes. A few states, including New Jersey, New York, and Texas, have provided grant money for providers to “edenize” their facilities, but it is not clear what the effect has been (Stone & Wiener, 2001).

5. CONCLUSIONS

Improving the quality of long-term care is one of the enduring issues for older people and younger persons with disabilities. Most public attention has focused on nursing home care, but issues of inadequate quality remain in all sectors of long-term care. This paper explores three sets of issues that are important in setting national goals for quality improvement in long-term care:

- What are the important areas of concern for quality in long-term care?
- What is the status of the quality of long-term care?
- What are the pros and cons of various strategies to improve the quality of long-term care? What are specific initiatives implied by these strategies?

Quality Domains in Long-Term Care: What is Important to Consider?

Long-term care primarily consists of help with the activities of daily living (e.g., eating, bathing, dressing, transferring, and toileting) and the instrumental activities of daily living (e.g., help with shopping, housekeeping, using the telephone, money management, and transportation). As such, a great deal of long-term care is provided by unlicensed staff, such as certified nurse assistants, personal care attendants, and home health aides. Because of the highly intimate nature of the tasks and because they reflect how people want to live their lives, long-term care is highly individualistic and idiosyncratic. At the same time, many persons with disabilities have serious medical problems that require coordination with and involvement of the acute care sector.

The principal domains of long-term care are quality of care and quality of life:

- *Quality of care* refers to the technical competency of medical and nonmedical services.
- *Quality of life* refers to such factors as consumer choice and autonomy, dignity, individuality, comfort, and meaningful activity.

Both spheres are important, although quality of care has received most of the regulatory and measurement attention; quality of life is much talked about, but little measured, researched, or examined. Arguably, quality of life is what matters most to consumers. Some observers see a tradeoff between quality of care and quality of life, at least for some activities that improve quality of life but involve risk of adverse outcomes.

A variety of principles for improving quality in health and long-term care have been proposed. The Institute of Medicine panel on long-term care (2001a) emphasizes the importance of ensuring that long-term care is consumer centered, providing consumers with information, developing multidimensional measures of quality, and addressing both quality of care and quality of life. The Institute of Medicine panel on health care (2001b) focused on safety, effectiveness, patient-centeredness, timeliness, efficiency, and equity as being components of quality.

The Status of Quality in Long-Term Care: How Will We Know If We Are Making Progress?

Over the past two decades, enormous progress has been made in developing quality measures for long-term care, but there is still a long way to go. A substantial amount of resources have been invested in developing measures of quality in long-term care and in implementing individual-level data systems that allow for quality assessments of individual providers, but the availability and quality of data differ by type of provider:

- *Nursing homes and, to a substantial but lesser extent home health agencies, have been the focus of these data and measurement efforts.* For nursing homes in particular, a wealth of data and measures exist. Nevertheless, questions remain about whether this information is reliable and valid and not subject to manipulation by providers and to variations in inspection stringency by state surveyors. To ensure the accuracy of the Minimum Data Set data, which are used for both reimbursement and quality assurance, the Centers for Medicare & Medicaid Services (CMS) may wish to consider increasing its data quality efforts and doing more checks of the accuracy of provider submissions.
- *In contrast, no data on quality are available at the national level and in most states for nonskilled home care, assisted living facilities, and other residential settings.* An honest assessment is that the quality of home and community-based services remains a black box about which we know extremely little. For nonskilled home care, assisted living, and other forms of residential care, measurement of quality remains a major task on which relatively little research has been done, despite the rapidly growing level of expenditures. CMS, the Agency for Healthcare Research and Quality (AHRQ), the National Institute on Aging, and private foundations should consider funding research projects that develop valid and reliable methods of measuring the quality of noninstitutional services, which will in turn require substantial additional research and an investment in quality assurance systems by the federal and state governments.
- *Finally, quality measurement initiatives in long-term care have focused on quality of care rather than quality of life.* We know much more about individuals' ability to transfer from their bed to a chair than we do about whether nursing facility residents feel that they have control over their lives. Long-term care is, by definition, over an extended period, and living in a nursing home or other residential facility completely reconfigures the lives of people who live there. Thus, while being able to measure quality of care provided by nursing homes and home health agencies is a major achievement, the essence of long-term care is in quality of life. Measuring quality of life is extraordinarily difficult, however, because it is almost entirely subjective. The cognitive impairment of many people needing long-term care adds to the difficulty in exploring this domain. To address these problems and to help resolve them, CMS, AHRQ, the National Institute on Aging, and private foundations could consider funding research projects that develop valid and reliable measures of quality of life across all long-term care settings.

Strategies to Improve Quality of Care: How Do We Get There from Here?

Quality of care and quality of life in long-term care will not improve simply because policymakers, providers, consumers, and commissions will it so. For change to occur, mechanisms need to be implemented by which incentives and mandates work together to achieve behavioral change on the part of providers. On this point, there is no shortage of proposed initiatives to improve quality of care and quality of life; some of the main strategies and their pros and cons are summarized in *Table 5-1*. These strategies include:

- Mandatory approaches that are external to providers:
 - Strengthening the regulatory process.
 - Strengthening the caregiving workforce (e.g., establishing minimum staffing ratios in nursing homes).
- Voluntary approaches that are external to providers:
 - Providing consumers and others with more information about the quality of services provided by individual providers.
 - Strengthening consumer advocacy.
 - Changing Medicare and Medicaid reimbursement systems.
- Voluntary strategies that are internal to providers:
 - Developing and implementing practice guidelines.
 - Changing the organizational culture of long-term care providers.

Table 5-2 presents a range of specific initiatives derived from these strategies.

Table 5-1. Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care

Strategy	Pros	Cons	Other Comments
Mandatory Approaches that are External to Providers			
Strengthening the regulatory process	Builds on large existing system of quality assurance for nursing facilities and home health agencies. Great deal of data available. Main approach used in many other countries.	Many regulations address paperwork and structural requirements rather than outcomes. Nursing home regulations inconsistently interpreted and applied across geographic areas. May stifle innovation. Enforcement often weak for nursing facilities.	Federal government dominates regulation of nursing facilities and home health agencies; states dominate regulation of other services. Currently, extensive regulation for nursing facilities and home health agencies, but little regulation of home and community-based services.
Strengthening the caregiver workforce	Current staffing in nursing facilities below recommended levels. Training requirements for paraprofessional staff minimal or absent. Workers receive low wages and few fringe benefits, making recruitment and retention difficult.	Organization and management of services also very important. Expensive to implement. No research on effects of training on quality. Little research on effects of higher wages and benefits on quality of care. May create barriers to entry.	Long-run demographic changes will make recruitment and retention more difficult over time.

(continued)

Table 5-1. Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care (Continued)

Strategy	Pros	Cons	Other Comments
Voluntary Approaches that are External to Providers			
Providing consumers with more information	<p>CMS provides a great deal of nursing home and home health information to consumers on websites.</p> <p>Makes market work better by encouraging competition on quality.</p> <p>For current nursing home and home health care, low-cost initiative.</p>	<p>Little research evidence on the effectiveness of this approach.</p> <p>Structural aspects of market may reduce possibility of competition on quality.</p> <p>Consumers may not be able to use information.</p> <p>Current data are focused on quality of care rather than quality of life.</p>	<p>Little or no quality data available for home and community-based services, including assisted living facilities.</p>
Strengthening consumer advocacy	<p>Provides a counterbalance to nursing home industry.</p> <p>Represents views of consumers.</p> <p>Provides resolution to individual complaints.</p>	<p>No research on effectiveness.</p> <p>Volunteers often lack technical expertise.</p> <p>Fear of retaliation by providers may limit complaints. By consumers.</p>	<p>Most existing consumer advocacy on quality issues focuses on nursing homes rather than home and community-based services.</p>
Reforming the payment systems for Medicare and Medicaid	<p>A reformed payment system could provide incentives for quality care and a payment level sufficient to cover the costs of efficient provision of quality care.</p> <p>Government can change payment system.</p> <p>Providers depend heavily on government financing, making them sensitive to government reimbursement system.</p>	<p>Little research evidence on the effectiveness of this approach.</p>	<p>This is a growing area of experimentation and demonstration.</p>

(continued)

Table 5-1. Summary of Strategies to Improve Quality of Care and Quality of Life in Long-Term Care (Continued)

Voluntary Strategies that are Internal to Providers			
Developing and implementing practice guidelines	Low-tech aspects of long-term care make guidelines potentially very useful. Many guidelines already exist.	Some guidelines raise costs. Accurate reporting on use of guidelines may expose providers to surveyor sanctions. Limited federal and state government policy levers.	Most guidelines geared to quality of care rather than quality of life, and to nursing homes.
Changing the organizational culture of long-term care providers	Systematically changes culture of care to focus on consumer needs and empowering workers. Addresses many critiques of nursing homes.	Little research on effectiveness. Replicability unclear. May result in higher costs. Limited federal and state policy levers.	Focus has been on nursing homes; little attention on home health or home and community-based services.

Table 5-2. Options for Improving Quality of Long-Term Care

Mandatory Approaches that are External to Providers
<p>Reform the regulatory process</p> <ul style="list-style-type: none"> ▪ Increase funding for the federal survey and certification process for nursing homes and home health agencies. ▪ Further standardize the inspection process to decrease geographic and surveyor variation in the citation of nursing home deficiencies. ▪ More aggressively enforce federal and state quality standards, with the goal of forcing poor-quality providers to close or change ownership. Increase use of intermediate sanctions and receiverships. ▪ Reduce regulatory burdens on consistently high-quality facilities (e.g., survey high-quality facilities less often). ▪ Increase the regulatory focus on outcomes. Review existing federal and state regulations to reduce unnecessary paperwork and micromanaging of long-term care providers. ▪ Review federal and state regulations to identify requirements that adversely affect quality of life in nursing homes and residential care facilities. ▪ Monitor quality of home and community-based services more systematically. ▪ Fund and conduct research on the effect of the regulatory process on quality of nursing home care and home and community-based services.

(continued)

Table 5-2. Options for Improving Quality of Long-Term Care (Continued)

Mandatory Approaches that are External to Providers (continued)

Strengthening the caregiver workforce

- Establish quantitative minimum staffing levels in nursing homes at least as high as the national average, if not higher. Establish minimum staffing levels for registered nurses in nursing homes that are higher than the national average.
- Increase state and federal minimum training requirements for certified nurse assistants and home health aides.
- Impose and strengthen state minimum training requirements for nonskilled workers in residential care facilities and home care.
- Establish foundation and federal/state programs to recruit staff to long-term care and to train the long-term care workforce.
- Increase wages and benefits for long-term care workers through Medicare and Medicaid wage pass-throughs.
- Increase federal funding for training informal caregivers under the U.S. Administration on Aging's National Family Caregiver Support Program and the Alzheimer's Disease Demonstration Grants to States program.
- Fund and conduct research on the determinants of recruitment and retention in long-term care and its effect on quality.

Voluntary Approaches that are External to Providers

Providing consumers with more information

- More highly publicize CMS's Nursing Home Compare and Home Health Compare websites.
- Continue to refine the Nursing Home Compare and Home Health Compare websites, adding more measures that focus on quality of life. Work towards measures of quality that consumers can easily understand.
- Developing consumer-information websites for home care and residential care facilities at the state level.
- Complete the development and consider implementation of the Nursing Home Consumer Assessment of Health Plans Survey.
- Fund and conduct research on the effect of consumer information on quality of care.

Reforming the payment systems for Medicare and Medicaid

- Ensure that the design of prospective payment systems for Medicare and Medicaid does not include incentives to reduce expenditures for client care without regard to quality.
- Ensure that Medicare and Medicaid reimbursement levels are adequate to provide high-quality care.
- Refine nursing home and home health prospective payments systems to incorporate some financial incentives for higher-quality care. Extend CMS pay-for-performance demonstrations to all major portions of the long-term care services system.
- Fund and conduct research on the effect of Medicare and Medicaid reimbursement on quality in nursing homes and other long-term care providers.

Strengthening consumer advocacy

- Increase funding for the U.S. Administration on Aging's Long-Term Care Ombudsman program.
- Establish foundation programs to support consumer advocates for long-term care quality.

(continued)

Table 5-2. Options for Improving Quality of Long-Term Care (Continued)

Voluntary Strategies that are Internal to Providers (continued)

Developing and implementing practice guidelines

- Disseminate more widely practice guidelines and protocols.
 - Fund and conduct research to develop cost-effective practice protocols.
-

Changing the organizational culture of long-term care providers

- Develop and demonstrate new methods to re-orient the overall culture and process of care in nursing homes and other providers to improve the quality of life of residents and clients.
 - Fund research on the effectiveness of culture change on the quality and cost of long-term care.
-

In evaluating these options for improvement, several factors should be considered:

- *Long-term care is a shared responsibility among the federal and state governments, providers, and consumers.* Public sector funding overwhelmingly dominates the financing of long-term care. The federal and state governments share regulatory responsibility for the long-term care services that Medicare and Medicaid fund. The federal government dominates the quality assurance standards and process for nursing homes and home health agencies, but states play a critical role in carrying out federal mandates. In addition, states inspect nursing homes and home health agencies, have day-to-day contact with facilities, and initiate enforcement actions; their role is much larger than just a mechanical implementation of the federal rules. In addition, states have virtually complete autonomy in ensuring the quality of nonskilled home and community-based services, including residential care facilities.

Providers of services, of course, have a managerial and ethical responsibility to provide good-quality care; consumers want high-quality care and have the duty to insist on it.

- *The extent of regulation is very uneven across providers.* Nursing homes are subject to substantial regulation, while home health agencies are less regulated. Many observers believe that current nursing home standards are not adequately enforced, reflecting a lack of political will to do so. Other forms of home and community-based services, such as personal care, assisted living facilities, and adult day care programs, are much less regulated. Consumer-directed home care, where individual consumers hire, direct, and fire their own workers, is even less regulated, both here and in other countries (Tilly & Wiener, 2001; Wiener, Tilly & Cuellar, 2003).
- *Data to measure quality are relatively well developed for nursing homes and home health agencies but are almost entirely lacking for a wide range of home and community-based services.* More and more people are receiving home care and residing in residential care facilities, such as assisted living facilities. In addition, the increasing emphasis on Medicaid home and community-based service waivers, which are limited to persons who need institutional-level care, means that the disability level of people receiving care in the community is likely

to be increasing. Currently, policymakers and government regulators have very little information about the quality of services that people receive at home.

- *Several options for reform—including strengthening the caregiving workforce, changing Medicare and Medicaid reimbursement systems, and developing and implementing practice guidelines—require substantially more resources.* Given the heavy dependence of long-term care on Medicare and Medicaid, additional funding would be required from federal and state governments. The current fiscal and political environment makes additional public funding difficult.
- *Despite the plethora of possible approaches to improve quality of care, the existing research literature does not provide much guidance about their relative effectiveness.* CMS, AHRQ, the National Institute on Aging, the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services, and private foundations should consider funding research that would rigorously evaluate the impact of different approaches to quality assurance, including the Eden Alternative and other organizational culture change initiatives, the effectiveness of providing consumer information, and the impact of raising wages and providing fringe benefits to long-term care workers. These approaches are highly appealing, but it is not known whether they would actually improve quality of care or how much they would cost. These studies should take a broad view of costs and include the potential impact on the acute care sector of improved quality in long-term care.
- *Many quality initiatives are geared to punishing or avoiding inferior-quality care, rather than establishing incentives for providers to provide good—even high-quality—care.* Demonstration projects could be developed that provide financial incentives to high quality of care. Although conceptually appealing, these projects face substantial technical problems, and the risk of providing financial rewards to providers that are of low quality is not trivial. However, government regulation is a blunt instrument, and the inevitable reality is that surveyors can only directly observe care a very small percentage of the time. Ultimately, long-term care providers are responsible for the care provided in their facilities and by their organizations.
- *Several of the strategies for improving quality presuppose a relatively sophisticated ability on the part of nursing homes and other long-term care providers to develop, analyze, and use data and then to implement management changes based on those data.* Some long-term care providers may not have the organizational capacity required to undertake these approaches. To address this problem, it is worth considering the proposal by the Committee on Improving Quality in Long-Term Care of the Institute of Medicine to establish “centers for the advancement of quality in long-term care,” which would initiate research, demonstration, and training programs for providers to redesign care processes consistent with best practices and improvements in quality of life (Institute of Medicine, 2001a).
- *The political saliency of long-term care quality issues and the consistency of government attentiveness to the issue are uneven.* Interest by policymakers tends

to be cyclical. Quality of care scandals publicized by the media tend to focus attention on these issues only for a limited period of time. All too quickly, the stories about poor-quality care subside, and the topic fades from attention, especially for top policymakers who have competing demands for their attention. It is hard to make progress without sustained attention by high-level policymakers.

Although the quality of care and life supplied by many long-term care providers is good or excellent, inadequate care is all too common. And with the aging of the baby boom generation, more of us are likely to spend part of our lives needing long-term care. Thus, whether the quality of that care is good or bad will affect many of us in a very personal way. Improving quality will not be easy, but it can be done.

6. REFERENCES

- Abt Associates, Inc. (2004). *National nursing home quality measures user's manual*. Cambridge, MA: Abt Associates, Inc.
- Administration on Aging (n.d.). *A statistical profile of Hispanic older Americans aged 65+*. Available at: http://www.aoa.gov/press/fact/pdf/fs_hispanic_elderly.pdf.
- Administration on Aging (2004). *Promising practices in the field of caregiving: 28 national innovations programs, 11 projects of national significance*. Available at: http://www.aoa.gov/prof/aoaprogram/caregiver/careprof/nfcsp_projects/PromisingPractices.pdf.
- Administration on Aging (2007). *2005 national ombudsman reporting system data tables*. Retrieved March 30, 2007, from http://www.aoa.gov/prof/aoaprogram/elder_rights/LTCombudsman/National_and_State_Data/2005nors/2005nors.asp.
- Alexih, L.M.B., Corea, J., & Kennell, D.L. (1995). Implications of health care financing, delivery and benefit design for persons with disabilities. In J.M. Wiener, S.B. Clauser, and D.L. Kennell (eds.), *Persons with Disabilities: Issues Health Care Financing and Services Delivery*, pp. 95-116. Washington, DC: The Brookings Institution.
- American Health Care Association (2006). *Trends in nursing facility characteristics*. Washington, DC: American Health Care Association. Available at: http://www.ahca.org/research/oscar/trend_graph_facilities_characteristics_200612.pdf.
- American Health Care Association (2007a). *Nursing facility patients by payor—percentage of patients, CMS OSCAR data, current surveys, December 2006*. Available at: http://www.ahca.org/research/oscar/rpt_payer_200612.pdf.
- American Health Care Association (2007b). *Nursing facility total, average and median number of patients per facility and ADL dependence, CMS OSCAR data current surveys, December 2006*. Washington, DC. Available at: http://www.ahca.org/research/oscar/rpt_average_ADL_200612.pdf.
- Anderson, G.F., & Hovarth, J. (2004). The growing burden of chronic disease in America. *Public Health Reports*, 119(3), 263-270.
- Appleby, J. (2004, May 26). Sexual assaults haunt families of elderly victims. *USA Today*.
- APS Healthcare, Inc. (2003). *Family care independent assessment: An evaluation of access, quality and cost-effectiveness for calendar year 2002*. Madison, WI: APS Healthcare, Inc.
- Arling, G., Kane, R.L., Lewis, T., & Mueller C. (2005). Future development of nursing home quality indicators. *Gerontologist*, 45, 147-156.

- Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18(2), 182-188.
- Barr, J.K., Boni, C.E., Kochurka, K.A., Nolan, P., Petrillo, M., Sofaer, S., & Waters, W. (2002). Public reporting of hospital patient satisfaction: The Rhode Island experience. *Health Care Financing Review*, 23(4), 51-70.
- BDO Seidman (2006). *A report on shortfalls in Medicaid financing for nursing home care*. Washington, DC: American Health Care Association. Available at: <http://www.ahca.org/brief/seidmanstudy0606.pdf>.
- Beck, C., Heacock, P., Mercer, S.O., Wallis, R.C., Rapp, C. G., & Vongelpohl, T.S. (1997). Improving dressing behavior in cognitively impaired nursing homes residents. *Nursing Research*, 46, 126-132.
- Benjamin, A.E., Matthias, R.E., & Franke, T.M. (1998). *Comparing client-directed and agency models for providing supportive services at home*. Final report to the U.S. Department of Health and Human Services. Los Angeles: UCLA School of Public Policy.
- Bernard, S., Hampton, N., & Kreling, B. (2003). *Nursing Home CAHPS: Final report*. Report prepared for the Agency for Health Care Research and Quality. Research Triangle Park, NC: RTI International.
- Bishop, C.E. (1988). Competition in the market for nursing home care. *Journal of Health Politics, Policy and Law*, 13(2), 341-360.
- Bostick, J.E., Rantz, M.J., Flesner, M.K., & Riggs, C.J. (2006). Systematic review of studies of staffing and quality in nursing homes. *Journal of the American Medical Directors Association*, 7(6), 366-376.
- Buhr, G.T., & White, H.K. (2006). Quality improvement initiative for chronic pain assessment and management in the nursing home: A pilot study. *Journal of the American Medical Directors Association*, 7(4), 246-253.
- Carter, M.W., & Porell, F.W. (2006). Nursing home performance on select publicly reported quality indicators and resident risk of hospitalization: Grappling with policy implications. *Journal of Aging and Social Policy*, 18(1), 17-39.
- Centers for Medicare and Medicaid Services (2001). *Appropriateness of minimum staffing ratios in nursing homes. Report to Congress: Phase II final*. Report prepared by Abt Associates, Inc. Baltimore, MD: Centers for Medicare and Medicaid Services.
- Centers for Medicare & Medicaid Services (2002a). *Appropriateness of minimum staffing ratios in nursing homes. Report to Congress*. Baltimore, MD: Centers for Medicare & Medicaid Services.

- Centers for Medicare & Medicaid Services, Director, Disabled and Elderly Health Programs Group (2002b). *Quality of home and community-based services: The quality matrix and framework*. Letter to State Medicaid Directors. Baltimore, MD: Centers for Medicare & Medicaid Services.
- Centers for Medicare & Medicaid Services (2004a). *Home Health Compare website*. Available at: <http://www.medicare.gov/HHCompare/Home.asp?version=default&browser=IE%7C6%7CWin2000&language=English&defaultstatus=0&pagelist=Home>.
- Centers for Medicare & Medicaid Services (2004b). *Nursing Home Compare website*. Available at: <http://www.medicare.gov/NHCompare/Static/Related/DataCollection.asp?dest=NAV|Home|DataDetails|DataCollection#TabTop>.
- Centers for Medicare & Medicaid Services (2005). *Medicare “pay for performance (P4P)” initiatives*. Available at: <http://www.cms.hhs.gov/apps/media/press/release.asp?Counter=1343>.
- Centers for Medicare & Medicaid Services (2007). *Groundbreaking Medicare payment demonstration results in substantial improvement for hospital patient care*. Available at: http://www.cms.hhs.gov/apps/media/press_releases.asp.
- Chernew, M., & Scanlon, D.P. (1998). Health plan report cards and insurance choice. *Inquiry*, 35(1), 9-22.
- Coates, B. (2007, April 5). Lawmaker asks why Stephens didn't answer letters from relatives of man who died at veterans home. *Arizona Capitol Times*.
- Cohen, J.W., & Spector, W.D. (1996). The effect of Medicaid reimbursement on quality of care in nursing homes. *Journal of Health Economics*, 15, 23-28.
- Colon-Emeric, C., Schenck, A., Gorospe, J., McArdle, J., Dobson, L., DePorter, C., & McConnell, E. (2006). Translating evidence-based falls prevention into clinical practice in nursing facilities: Results and lessons from a quality improvement collaborative. *Journal of the American Geriatrics Society*, 54(9), 1414-1418.
- Cousineau, M., Regan, C., & Kokkinis, A. (2000). *A crisis for caregivers: Health insurance out of reach for Los Angeles home care workers*. Oakland, CA: California Healthcare Foundation.
- Crown, W., Ahlburg, D.A., & MacAdam, M. (1995). The demographic and employment characteristics of home care aides: A comparison with nursing home aides, hospital aides, and other workers. *Gerontologist*, 35(2), 162-170.
- Dalby, D.M., Hirdes, J.P., & Fries, B.E. (2005). Risk adjustment methods for Home Care Quality Indicators (HCQIs) based on the minimum data set for home care. *BMC Health Services Research*, 5, 7.

- Decker, F.H., Gruhn, P., Matthews-Martin, L., Dollard, K.J., Tucker, A.M., & Bizette, L. (2003). *2002 AHCA survey nursing staff vacancy and turnover in nursing homes*. Washington, DC: American Health Care Association.
- Dilanian, K. (2007, February 25-28). A failure to care (four-part series). *Philadelphia Inquirer*.
- Edelman, T. (2001). *Providing technical assistance to facilities*. Washington, DC: Center for Medicare Advocacy.
- Ehrenberg, R., & Smith, R. (1997). *Modern labor economics: Theory and public policy*. New York: Addison Wesley.
- Foster, L., Brown, R., Phillips, B., Schore, J., & Carlson, B.L. (2003). Improving the quality of Medicaid personal assistance through consumer direction. *Health Affairs*, Jan-Jun(Suppl), W3-162-75.
- Fries, B.E., Hawes, C., Morris, J.N., Phillips, C.D., Mor, V., & Park, P.S. (1997). Effect of the national resident assessment instrument on selected health conditions and problems. *Journal of the American Geriatrics Society*, 45(8), 994-1001.
- Geron, S.M. (1996). Using measures of subjective well-being and client satisfaction in health assessments of older persons. *Health Care in Later Life*, 1(6), 185-196.
- Geron, S.M., Smith, K., Tennstedt, S., Jette, A., Chassler, D., & Kasten, L. (2000). The Home Care Satisfaction Measure: A client-centered approach to assessing the satisfaction of frail older adults with home care services. *Journal of Gerontology: Social Sciences*, 55B(5), S259-S270.
- Grabowski, D.C. (2001). Medicaid reimbursement and quality of nursing home care. *Journal of Health Economics*, 20, 549-69.
- Grabowski, D.C. (2004). A longitudinal study of Medicaid payment, private-pay price and nursing home quality. *International Journal of Health Care Finance and Economics*, 4, 5-26.
- Grabowski, D.C., & Angelelli, J.J. (2004). The relationship of Medicaid payment rates, bed constraint policies, and risk-adjusted pressure ulcers. *Health Services Research*, 39(4 Pt 1), 793-812.
- Grabowski, D.C., Angelelli, J.J., & Mor, V. (2004). Medicaid payment and risk adjusted nursing home quality measures. *Health Affairs*, 23(5), 243-52.
- Harrington, C., & Carrillo, H. (2000). *Analysis of HCFA's On-Line Survey, Certification and Reporting (OSCAR) system data*. San Francisco: University of California.
- Harrington, C., Carrillo, H., & LaCava, C. (2006). *Nursing facilities, staffing, residents, and facility deficiencies, 1999 through 2005*. San Francisco: University of California.

- Harrington, C., Kovner, C., Mezey, M., Kayser-Jones, J., Burger, S., Mohler, M., Burke, R., & Zimmerman, D. (2000a). Experts recommend minimum nurse staffing standards for nursing facilities in the United States. *Gerontologist*, (1), 5-16.
- Harrington, C., O'Meara, J., Kitchener, M., Schnelle, J.F., Simmons, S., Jensen, B.B., Saliba, D., Zimmerman, D.R., & Rudolph, B. (2002). *California nursing home search: A policy paper*. San Francisco: University of California.
- Harrington, C., O'Meara, J., Kitchener, M., Simon, L.P., & Schnelle, J.F. (2003). Designing a report card for nursing facilities: What information is needed and why. *Gerontologist*, 43(Special Issue II), 47-57.
- Harrington, C., Zimmerman, D., Karon, S.L., Robinson, J., & Beutel, P. (2000b). Nursing home staffing and its relationship to deficiencies. *Journal of Gerontology: Social Sciences*, 55(5), S278-287.
- Harris-Kojetin, L., Lipson, D., Fielding, J., Kiefer, K., & Stone, R.I. (2004). *Recent findings on frontline long-term care workers: A research synthesis 1999–2003*. Washington, DC: Institute for the Future of Aging Services, Association of Homes and Services for the Aged. Available at: <http://aspe.hhs.gov/daltcp/Reports/insight.htm>.
- Hawes, C., Mor, V., Phillips, C.D., Fries, B.E., Morris, J.D., Steel-Friedlob, E., Greene, A.M., & Nennestiel, M. (1997). The OBRA-87 nursing home regulations and implementation of the resident assessment instrument: Effect on process quality. *Journal of the American Geriatrics Society*, 45(8), 977-985.
- Hawes, C., Rose, M., & Phillips, C.D. (2000). *A national study of assisted living for the frail elderly: Results of a national survey of facilities*. Report prepared for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at: <http://aspe.hhs.gov/daltcp/reports/facres.htm>.
- Health Care Financing Administration (1998). *Report to Congress: Study of private accreditation (deeming) of nursing homes, regulatory incentives and non-regulatory initiatives, and effectiveness of the survey and certification system*. Baltimore: U.S. Department of Health and Human Services. Available at: <http://www.hcfa.gov/medicaid/deemovw.htm>.
- Health Care Financing Administration (2000). *Report to Congress: Appropriateness of minimum nurse staffing ratios in nursing homes*. Baltimore: U.S. Department of Health and Human Services.
- Hibbard, J.H., Stockard, J., & Tusler, M. (2002). Does publicizing hospital performance stimulate quality improvement efforts? *Health Affairs*, 22(2), 84-94.
- Howes, C. (2002). The impact of a large wage increase on the workforce stability of IHSS home care workers in San Francisco County. New London, CT: Connecticut College.

- Infield, D.L. (2005). *States' experiences implementing consumer-directed home & community services: Results of the 2004 Survey of State Administrators, Opinion Survey & Telephone Interviews*. National Association of State Units on Aging and the National Council on the Aging. Available at: http://www.nasua.org/pdf/20026_text.pdf.
- Institute of Medicine (1995). *Real people, real problems: Evaluation of the long-term care ombudsman program of the Older Americans Act*. Washington, DC: National Academy Press.
- Institute of Medicine (1996). *Nursing staff in hospitals and nursing homes: Is it adequate?* Washington, DC: National Academy of Sciences.
- Institute of Medicine (2001a). *Improving the quality of long-term care*. Washington, DC: National Academy of Sciences.
- Institute of Medicine (2001b). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy of Sciences.
- Jenkins, R., O'Keeffe, J., Carder, P., and Brown-Wilson, K. (2006). *A study of negotiated risk agreements in assisted living facilities: Final report*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation. Available at: <http://aspe.hhs.gov/daltcp/reports/2006/negrisk.htm>.
- Johnson, R.W. & Wiener J.M. (2006). *A profile of older Americans and their caregivers*. Washington, DC: The Urban Institute.
- Kane, R.A. (2001). Long-term care and a good quality of life: Bringing them closer together. *Gerontologist*, 41(3), 293-304.
- Kane, R.A. (2003). Definition, measurement, and correlates of quality of life in nursing homes: Toward a reasonable practice, research, and policy agenda. *The Gerontologist*, 43(Special Issue II), 28-36.
- Kane, R.L., Arling, G., Mueller, C., Held, R., & Cooke, V. (2007). A quality-based payment strategy for nursing home care in Minnesota. *The Gerontologist*, 47, 108-115.
- Kane, R.L., Bershadsky, B., Kane, R.A., Degenholtz, H.H., Liu, J., Giles, K., & Kling, D.C. (2004). Using resident reports of quality of life to distinguish among nursing homes. *Gerontologist*, 44(5), 624-632.
- Kane, R.L. & Huck, S. (2000). The implementation of the EverCare demonstration project. *Journal of the American Geriatrics Society*, 44, 218-228.
- Kane, R.A., Kling, K.C., Bershadsky, B., Kane, R.L., Giles, K., Degenholtz, H.B., et al. (2003). Quality of life measures for nursing home residents. *Gerontologist*, 44(5), 624-632.

- Khatutsky, G.A., Anderson, W.L., & Wiener, J.M. (2006). Personal care satisfaction among aged and physically disabled Medicaid beneficiaries. *Health Care Financing Review*, 28(1): 69-86.
- Knutson, D.J., Kind, E.A., Fowles, J.B., & Adlis, S. (1998). Impact of report cards on employees: A natural experiment. *Health Care Financing Review*, 20, 5-27.
- Komisar, H.L., Hunt-McCool, J. & Feder, J. (1997-1998). Medicare spending for elderly beneficiaries who need long-term care. *Inquiry*, 34(4), 302-310.
- LaPlante, M.P., Harrington, C., & Taewoon, K. (2002). Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. *Health Services Research*, 37(2), 397-416.
- Lee, R.H., Gajewski, B.J., & Thompson, S. (2006). Reliability of the nursing home survey process: A simultaneous survey approach. *Gerontologist*, 46(6), 772-780.
- Link, G., Dize, V., Folkemer, D., & Curran, C. (2006). *Family caregiver support: State facts at a glance*. Washington, DC: The National Conference of State Legislatures.
- Liu, K., Manton, K.G., & Aragon, C. (2000). Changes in home care use by disabled elderly persons: 1982–1994. *Journal of Gerontology: Social Sciences*, 55B(4), S245-S253.
- Maryland Health Care Commission (2006). Nursing home family satisfaction survey pilot statewide results.
- Mattimore, T.J., Wenger, N.S., Desbiens, N.A., Teno, J.M., Hamel, M.B., Liu, H., et al. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatrics Society*, 45, 818-824.
- McCormack, L.A., Anderson, W.L., Uhrig, J., Garfinkel, S., Sofaer, S., & Terrell, S. (2001). Health plan decision making in the Medicare population: Results from a national randomized experiment. *Health Services Research*, 36(6)(Part II), 133-149.
- McCoy, K. (2004, May 26). Job applicants not always screened. *USA Today*.
- McCoy, K., & Appleby, J. (2004, May 26). Many facilities accept people who are too ill. *USA Today*.
- Mollica, R. (2002). *State assisted living policy: 2002*. Portland, ME: National Academy for State Health Policy.
- Mollica R.L. (2006). *Residential care and assisted living: State oversight practices and state information available to consumers*. AHRQ Publication No. 06-M051-EF. Rockville, MD: Agency for Healthcare Research and Quality.

- Mollica, R. & Johnson-Lamarche, H. (2005). *Residential care and assisted living compendium 2004*. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Available at: <http://aspe.hhs.gov/daltcp/reports/04alcom.htm>.
- Montgomery, R., & Kosloski, K. (1995). Respite revisited: Re-assessing the impact. In Katz, P.R., Kane, R.L., and Mezey, N.D. (eds.) *Quality of Care in Geriatric Settings*. New York: Springer Publishing Company.
- Morris, J.N., Moor, T., Jones, R., Mor, V., Angelelli, J., Berg, K., Hale, C., Morris, S., Murphy, K.M., & Rennison, M. (2002). *Validation of long-term and post-acute care quality indicators*. Cambridge, MA: Abt Associates.
- Mukamel, D.B., & Brower, C.A. (1998). The influence of risk adjustment methods on conclusions about quality of care in nursing homes based on outcome measures. *Gerontologist*, 38, 367-385.
- Mukamel, D.B., & Spector, W.D. (2002). The competitive nature of the nursing home industry: Price mark ups and demand elasticities. *Applied Economics*, 34, 413-420.
- Mukamel, D.B., & Spector, W.D. (2003). Quality report cards and nursing home quality. *Gerontologist*, 43(Special Issue II), 58-66.
- National Citizens' Coalition for Nursing Home Reform (1985). *A consumer perspective on quality care: The residents' point of view*. Washington, DC: National Citizens' Coalition for Nursing Home Reform.
- National Citizens' Coalition for Nursing Home Reform (1995). *Consumers' minimum standard for nurse staffing in nursing homes*. Washington, DC: National Citizens' Coalition for Nursing Home Reform.
- New York State Moreland Act Commission on Nursing Homes and Residential Facilities (1975). *Regulating nursing home care: The paper tigers*. Report of the New York State Moreland Act Commission.
- Noelker, L.S., & Harel, Z. (eds.). (2000). *Quality of life and quality of care in long-term care*. New York: Springer Publishing Company.
- Norton, E.C. (1992). Incentive regulation of nursing homes. *Journal of Health Economics*, 26(2), 105-128.
- Nyman, J.A. (1985). Prospective and cost-plus Medicaid reimbursement, excess demand and the quality of nursing homes. *Journal of Health Economics*, 4, 237-259.
- Nyman, J. (1988). Improving the quality of nursing home outcomes: Are adequacy- or incentive-oriented policies more effective? *Medical Care*, 26(12), 1158-1171.

- O'Keeffe, J., & Wiener, J.M. (2004). Public funding for long-term care services for older people in residential care settings. *Journal of Housing for the Elderly*, 18(3/4), 51-80.
- O'Keeffe, J., Wiener, J.M., & Greene, A. (2005). *Consumer direction initiatives of the FY2001 and FY2002 systems change grantees: Progress and challenges*. Report to the Centers for Medicare & Medicaid Services. Research Triangle Park, NC: RTI International.
- Phillips, C.D., Hawes, C., Mor, V., Fries, B.E., Morris, J.D., & Nennestiel, M. (1996). Facility and area variation affecting use of physical restraints in nursing homes. *Medical Care*, 34(11), 1149-1162.
- Phillips, C.D., Morris, J.D., Hawes, C., Fries, B.E., Mor, V., Nennestiel, M., & Iannacchione, V. (1997). Association of the resident assessment instrument with changes in function, cognition, and psychosocial status. *Journal of the American Geriatrics Society*, 45(8), 986-993.
- Porell, F., & Caro, F.G. (1998). Facility-level outcome performance measures for nursing homes. *Gerontologist*, 38, 665-683.
- Port, C.L. (2006). Informal caregiver involvement and illness detection among cognitively impaired nursing home residents. *Journals of Gerontology: Series A: Biological Sciences and Medical Sciences*, 61A(9), 970-974.
- Rabig, J., Thomas, W., Kane, R.A., Cutler, L.J., and McAlilly, S. (2006). Radical redesign of nursing homes: Applying the Green House concept in Tupelo, Mississippi. *Gerontologist*, 46, 533-539. Available at: <http://gerontologist.gerontologyjournals.org/cgi/content/abstract/46/4/533>.
- Robert Wood Johnson Foundation (2002). Care for the caregivers program includes support groups and training, grant results. Princeton, NJ. Available at: <http://www.rwjf.org/reports/grr/030340.htm>.
- Rogers, J.C., Holm, M.B., Burgio, L.D., Granieri, E., Hsu, C., Hardin, J.M., & McDowell, B.J. (1999). Improving morning care routines of nursing home residents with dementia. *Journal of the American Geriatrics Society*, 47(9), 1049-1057.
- Rogers, S., & Komisar, H. (2003). Who needs long-term care? *Fact Sheet*. Washington, DC: Georgetown University.
- RTI International (2003). *CAHPS instrument for persons residing in nursing homes: Final report*. Report prepared for the Agency for Healthcare Research and Quality. Research Triangle Park, NC: RTI International.
- Schnelle, J.F., Cruise, P.A., Rahman, A., & Ouslander, J.G. (1998). Developing rehabilitative behavioral interventions for long-term care: Technology transfer, acceptance and maintenance issues. *Journal of the American Geriatrics Society*, 46, 771-777.

- Schnelle, J.F., Ouslander, J.G., & Cruise, P.A. (1997). Policy without technology: A barrier to changing nursing home care. *Gerontologist*, 37(4), 527-532.
- Schnelle, J.F., Ouslander, J.G., & Simmons, S.F. (2006). Direct observations of nursing home care quality: Does care change when observed? *Journal of the American Medical Directors Association*, 7(9), 541-544.
- Schore, J., Foster, L., and Phillips, B. (2007). Consumer enrollment and experiences in the cash and counseling program. *Health Services Research*, 42(1)(Part II), 446-466.
- Scully, T.A. (2003). Testimony on nursing home quality. Testimony before the U.S. Senate Finance Committee. Washington, DC.
- Short, P., McCormack, L., Hibbard, J., Shaul, J., Harris-Kojetin, L., Fox, M., Damino, P., Uhrig, J., & Cleary, P. (2002). Similarities and differences in choosing health plans. *Medical Care*, 40(4), 1-14.
- Shugarman, L.R. & Brown, J.A. (2006b). *Nursing home selection: How do consumers choose? Volume I: Findings from Focus Groups of Consumers and Information Intermediaries*. RAND Corporation, Washington, DC: Office of Disability, Aging and Long-Term Care Policy, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. Available at: <http://aspe.hhs.gov/daltcp/reports/2006/chooseI.pdf>.
- Shugarman, L.R., & Garland, R. (2006a). *Nursing home selection: How do consumers choose? Volume II: Findings from the website content review*. Rand Corporation.
- Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Kennedy, G., Burwell, B., Mollica, R., & Williams, L. (2000). *Understanding Medicaid home and community services: A primer*. Report prepared for the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services for the George Washington University Center for Health Policy Research. Washington, DC: U.S. Department of Health and Human Services.
- Spillman, B.C., & Pezzin, L.E. (2000). Potential and active caregivers: Changing networks and the "sandwich generation." *The Milbank Quarterly*, 78(3), 347-374.
- 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.
- Stone, R.I., & Wiener, J.M. (2001). *Who will care for us? Addressing the long-term care workforce crisis*. Washington, DC: The Urban Institute.
- Stuart, M., & Weinrich, M. (2001). Home is where the help is: Community-based care in Denmark. *Journal of Aging and Social Policy*, 12(4), 81-101.
- Thomas, W.H. (1994). *The Eden Alternative: Nature, hope, and nursing homes*. Sherburne, NY: Eden Alternative Foundation.

- Tilly, J. & Wiener, J.M. (2001). Consumer-directed home and community services programs in eight states: Policy issues for older people and government. *Journal of Aging and Social Policy*, 12(4), 1-26.
- U.S. Bureau of Labor Statistics (2006). *Occupational outlook handbook, 2006–2007*. Washington, DC: U.S. Government Printing Office.
- U.S. Congressional Budget Office (2004a). *Financing long-term care for the elderly*. Washington, DC: U.S. Congressional Budget Office.
- U.S. General Accountability Office (2007). *Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents* (GAO-07-241). Washington, DC: U.S. Government Accountability Office.
- 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.
- U.S. House of Representatives Committee on Government Reform, Minority Staff, Special Investigations Division (2002). *HHS “Nursing Home Compare” website has major flaws*. Washington, DC: U.S. House of Representatives.
- U.S. Office of Management and Budget (2007). *Budget of the U.S. Government, fiscal year 2008, appendix*. Washington, DC: U.S. Government Printing Office.
- U.S. Senate Special Committee on Aging (1974). *Nursing home care in the United States: Failure in public policy: Introductory report*. Washington, DC: U.S. Government Printing Office.
- Vaiana, M.E., & McGlynn, E.A. (2002). What cognitive science tells us about the design of reports to consumers. *Medical Care Research and Review*, 59(1), 3-35.
- Weissert, W.G., Elston, J.M., Bolda, E.J., Zelman, W.N., Mutran, E., & Mangum, A.B. (1990). *Adult day care centers: Findings from a national survey*. Baltimore: The Johns Hopkins University Press.
- Weissert, W.G., Scanlon, W.J., Wan, T.T., & Skinner, D.E. (1983). Care for the chronically ill: Nursing home incentive payment experience. *Health Care Financing Review*, 5(2), 41-49.
- White, A., Hurd, D. Moore, T., Warner, D., Wu, N. & Sweetland, R. (2006). *Quality monitoring for Medicare global payment demonstrations: Nursing home quality-based purchasing demonstration, final design report*. Centers for Medicare & Medicaid Services Contract # 500-00-0032, T.O. # 1. Cambridge, MA: Abt Associates Inc.
- White, C. (2005). Medicare’s prospective payment system for skilled nursing facilities: Effects on staffing and quality of care. *Inquiry*, 42(4), 351-366.

- Wiener, J.M. (1981). *A sociological analysis of government regulation: The case of nursing homes*. Unpublished doctoral dissertation. Cambridge, MA: Harvard University, Department of Sociology.
- Wiener, J.M., Anderson, W.L. & Khatutsky, G.A. (In press). Are consumer-directed home care beneficiaries satisfied? Evidence from Washington State. *Gerontologist*.
- Wiener, J.M., Howe, A., Doyle, C., Cuellar, A.E., Campbell, J.C., & Ikegami, N. (2007). Quality assurance for long-term care: The experiences of England, Australia, Germany and Japan. Washington, DC: American Association for Retired Persons, Report #2007-05.
- Wiener, J.M., & Lutzky, S.M. (2001). Home and community-based services for older people and younger persons with physical disabilities in Wisconsin. Washington, DC: The Urban Institute.
- Wiener, J.M. & Stevenson, D.G. (1998). Repeal of the "Boren Amendment": Implications for quality of care in nursing homes. Assessing the New Federalism, Series A, No. A-30. Available at: <http://www.urban.org/UploadedPDF/anf30.pdf>.
- Wiener, J.M., & Sullivan, C.M. (1995). Long-term care for the younger population: A policy synthesis. In J.M. Wiener, S.B. Clauser, & D.L. Kennell (eds.), *Persons with disabilities: Issues in health care financing and service delivery* (pp. 291-324). Washington, DC: The Brookings Institution.
- Wiener, J.M., Tilly, J., & Alexih, L.M.B. (2002). Home and community-based services for older persons and younger adults with disabilities in seven states. *Health Care Financing Review*, 23(3), 89-114.
- Wiener, J.M., Tilly, J., & Cuellar, A.E. (2003). Consumer-directed home care in the Netherlands, Germany and England. Washington, DC: AARP. Available at: <http://www.aarp.org/research/>.
- Wisconsin Department of Health and Family Services (2001). *Family care quality, CMO member outcomes: The baseline assessment*. Madison, WI: Wisconsin Department of Health and Family Services.
- Yamada, Y. (2002). Profile of home care aides, nursing home aides, and hospital aides: Historical changes and data recommendations. *Gerontologist*, 42(2), 199-206.
- Zhang, X., & Grabowski, D.C. (2004). Nursing home staffing and quality under the nursing home reform act. *Gerontologist*, 44(1), 13-23.
- Zimmerman, D.R., Karon, S.I., Arling, G., Clark, B.R., Collins, T., Ross, R., & Sainfort, F. (1995). Development and testing of nursing home quality indicators. *Health Care Financing Review*, 16(4), 107-127.

National Commission for Quality Long-Term Care

The National Commission for Quality Long-Term Care is a nonpartisan independent body charged with examining long-term care in America. The appointed commissioners reflect a diversity of experience in government, academia, quality improvement, and long-term care. The Commission was convened in October 2004. It grew out of an industry-led initiative called *Quality First, A Covenant for Healthy, Affordable, and Ethical Long-Term Care*. Funding for the Commission's work is provided by the Alliance for Quality Nursing Home Care, the American Health Care Association, and the American Association of Homes and Services for the Aging. The Commission was originally convened and housed at the National Quality Forum, but is now an independent commission at The New School. For more information, visit www.ncqltc.org.

RTI International

RTI International is one of the world's leading research institutes with more than 2,600 individuals working in 40 countries. A major focus of the Institute is health care, ranging from the discovery of life-saving drugs to health care financing. RTI International has done research and policy analysis for the Centers for Medicare & Medicaid, the Centers for Disease Control and Prevention, the National Institutes of Health, the Administration on Aging, the Office of the Assistant Secretary for Planning and Evaluation/U.S. Department of Health and Human Services, the Robert Wood Johnson Foundation, and AARP. RTI International is headquartered in Research Triangle Park, North Carolina. For more information, visit www.rti.org.