

NATIONAL COMMISSION FOR QUALITY



LONG-TERM CARE

Long-Term Care Quality: Historical Overview and Current Initiatives

Report for the National Commission for Quality Long-term Care

**John Capitman, PhD, Walter Leutz, PhD,
Christine Bishop, PhD, and Rosemary Casler
Schneider Institute for Health Policy
Heller School for Social Policy and Management
Brandeis University**

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

The **National Commission for Quality Long-term Care** was established in late 2004, to evaluate the quality of long-term care in the United States, identify factors influencing the ability to improve quality of care, and recommend national goals for quality improvement in long-term care. Initial funding for the Commission is provided by the Alliance for Quality Nursing Home Care, the American Association of Homes and Services for the Aging, and the American Health Care Association. Additional information may be found at www.qualitylongtermcarecommission.org.

The **National Quality Forum** (NQF) a private, not-for-profit healthcare quality improvement organization, appointed members to the National Commission for Quality Long-term Care in consultation with leaders and advocates from the long-term care community. The NQF, acting in its role as a convener of a broad array of healthcare stakeholders, staffs and supports the commission but plays a neutral role in its activities, findings, and recommendations.

No part of this may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means electronic, mechanical, photocopying, recording or otherwise, without prior written permission of the National Quality Forum. Requests for permission to reprint or make copies should be directed to:

Permissions
National Quality Forum
601 Thirteenth Street, NW
Suite 500 North
Washington, DC 20005
Tel: 202.783.1300
Fax: 202.783.3434

www.qualityforum.org



Long-Term Care Quality: Historical Overview and Current Initiatives

Executive Summary

This report for the National Quality Forum explores the evolving definitions of quality long-term care (LTC), the initiatives that have sought to improve quality, barriers to achieving this goal, and emerging opportunities to accelerate efforts to ensure that chronically ill and physically disabled adults have access to information that enables them to evaluate and compare LTC quality and to receive quality LTC. The types of LTC covered in this report include: nursing home care, skilled home health care, and home-based and community-based supportive care (called “community care” herein), and supportive housing settings such as assisted living. Although these settings sometimes serve children and persons of any age with mental retardation/ development disabilities, or chronic mental illness/substance abuse, the National Quality Forum’s mandate for this initiative does not include the specialized service providers or delivery, regulation, and financing systems that specifically target children and adults whose LTC needs are not primarily associated with aging-related chronic diseases and associated physical disabilities.

Long-Term Care Quality: Historical Overview and Current Initiatives

Historical Overview

The general historical pattern in quality initiative in LTC can be characterized by three important shifts in focus. First, since the 1960s, LTC quality has been conceived by most using Donabedian's framework that associates quality with structures, processes, and outcomes of care (Donabedian 1985). Significantly, the focus of attention has shifted over time from concern with basic structural factors (such as fire hazards in facility construction) to process of care indicators (such as use of physical and chemical restraints) to outcome of care indicators (such as changes in functional status). The more recent increasing concerns with quality of life for LTC recipients can be viewed as an extension of this increasing focus on care outcomes.

Second, this period has seen a slow shift in the focus of public and private sector quality initiatives. In the early years, the focus was on the definition and measurement of quality aimed at sanctioning providers who failed to meet standards. More recently, total quality management (TQM) concepts have become more influential: quality initiatives seek to engage provider organizations in ongoing carefully monitored interventions intended to enhance care processes and improve care outcomes. Efforts to increase public awareness about quality expectations and performance are also part of this more current approach.

Third, although nursing home care remains the most expensive component of our nation's response to the needs and preferences of chronically ill and disabled elders, attention has increasingly focused on defining quality at least partially with respect to participant autonomy in selecting and directing care. Because many elders prefer to remain in community settings, quality is increasingly defined in terms of supporting this choice. With new attention to community care has also come stronger demands from regulators and consumer advocates to measure and ensure accessibility and quality of care in these diverse settings.

Outcome-Based Quality Indicators (OBQI)

OBQI approaches to quality assurance, which foster collection and dissemination of standardized measures of health and functional status complemented by continuing attention to structure and process measure are now the mainstream approach to enhancing quality in nursing homes, home care and even some community care venues. Yet researchers and policy analysts point to shortcomings in the underlying science and the coherence among established practices. Five sets of issues have received the most attention:

- Difficulty in consistently finding reliability and validity of Quality Indicators (QIs) in practice settings,
- The validity of QIs as indicators of quality,
- Uncertain linkages among measures,
- Weak regulation in many states, and
- Questionable impacts of OBQI on care outcomes.

Two additional critiques of the OBQI approach are also noted. First, it has been difficult to adapt this approach to meeting advocate and consumer demands for greater attention to autonomy and quality of life goals in nursing homes. Second, although the OBQI approach is now well-established in nursing homes and home health contexts, there has been little progress to date in exporting this model to housing-plus-service contexts, such as assisted living, and community care.

Long-Term Care Quality: Historical Overview and Current Initiatives

Barriers to LTC Quality Improvement

Reading the literature on quality improvement in LTC feels at times like an exercise in futility. In nursing homes, our current regulations (focused on inputs and assessments of adverse outcomes) have improved quality in measurable ways (e.g., less use of restraints), but experts do not think they do a good job distinguishing good homes from bad homes, or in helping homes get better. Moreover, improved outcomes in LTC have been harder to define than in acute care, so the focus has been primarily on avoiding bad outcomes: none of the demonstrations of the collaborative outcomes-based quality improvement approach has focused on fostering higher levels of functional status improvement or similar positive outcomes. The situation in home and community care is in some ways worse and in some ways better: worse because there is much less commitment to even a minimum standard of access and quality, but perhaps better from a firmer acknowledgement that quality of life and choice may be appropriate first-order goals for LTC quality initiatives.

Across all LTC services, there are ongoing challenges to quality improvement associated with personnel. The difficult nature of work in this sector, combined with relatively meager pay and benefits for direct-care workers, have been associated with periodic labor shortages and difficulties in worker retention, supervision, and continuous training.

Four sets of barriers to improving nursing home quality were identified: the medically oriented and regulatory conceptualization of quality, inadequate resources to support improvements, technological limits on what nursing homes can accomplish, and lack of clear impetus for change. Additional barriers in community care include: the lack of a national policy commitment to community care, the slow emergence of alternative models for financing and delivery of community care, and competing conceptions of quality in these services. Further, there are ongoing gaps in knowledge about issues such as:

- Controlling for case-mix in QI measurement
- Linking staffing, job designs, and performance
- Measures for quality of life/care satisfaction
- Linking quality of life/satisfaction with QIs
- Organizational factors associated with adoption of improved care processes
- Roles of federal and state sanctions in performance improvement
- Community care QI measures that account for preferences, informal caregivers, and inadequate care access
- Extension of QI measures to care continuity and coordination issues
- Addressing cultural and individual preferences in QI measures

Long-Term Care Quality: Historical Overview and Current Initiatives

Recommendations

I. Encourage a national policy discussion on LTC goals

- A. Access to community care and unmet needs: Not since the period between the Pepper Commission (Commission 1990) and the subsequent failure of the Clinton healthcare reform initiative has there been a sustained national debate on the accessibility of community care services (Wiener et al., 2001). Rather than a national policy that ensures access to quality community care for elders based on need, we have a poorly funded patchwork quilt of programs that leave many elders un-served and underserved. Difficulty in accessing needed care and the surprisingly high prevalence of unmet needs for assistance in daily living and disease management activities among elders recently discharged from services covered by Medicare and other insurance loom as quality challenges for community care. Difficulties in building and sustaining a community care workforce – a crucial element in LTC quality—have also been linked to the absence of a national framework for community care. Other industrialized countries, such as Germany and Japan, have concluded that social insurance for all long-term is needed. Whether or not such a universal approach will be selected in the US is unclear, in part because we have not created the circumstances for full-scale public exploration of this issue. LTC and other health providers and advocates need to lead an effort to increase public awareness of the extent of unmet needs among disabled elders, the importance of these needs, and the range of policy options for addressing these problems.
- B. Quality of life and quality of care in nursing homes and other housing-plus-services settings. Many of the current critiques of nursing home quality assurance initiatives focus on their predominant attention to medically oriented components of care quality, while lacking sufficient attention to the quality of life for residents. By contrast, private-sector assisted living has emerged as a largely unregulated market that offers elders many of the services of nursing homes in more pleasant settings that support resident autonomy. Yet these providers are not held accountable for offering care consistent with emerging process and outcome standards. One solution would be to extend the OBQI approach to housing-plus-service settings, irrespective of payment source, while investing the needed public resources and attention to creating more normal and engaged lives for nursing home residents. Yet some critics of nursing home care and advocates for assisted living view these divergent patterns as positive impacts of a free market: individuals are given the choice among very different types of services. The National Commission for Quality Long-term Care and others could foster a real national debate on these issues to articulate a clearer basis for quality long-term care. One outcome of such a debate might be the articulation of a “bill of rights” for disabled adults that emphasizes more accurate disclosure by assisted living facilities with respect to process and outcome measures of care quality in relationship to nursing facility quality of care indicators, while ensuring that nursing facility regulation and quality improvement target creation of more normal and engaged lives for residents. Alternatively, such a national dialogue might conclude that public investment and regulation should continue to primarily target avoidance of unwarranted negative outcomes, while acknowledging that we as a nation are not committed to ensuring that elders who cannot afford private services can also experience a meaningful and “normal” quality of life.

2. National Demonstration of Nursing Home Culture Change Models

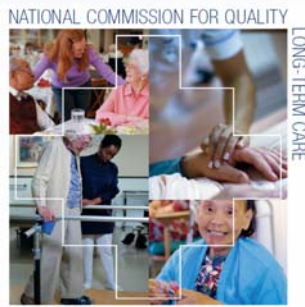
The Wellspring demonstrations in Wisconsin and similar proposals provide tantalizing glimpses of how nursing home culture, operations, and outcomes may be reoriented and seem to imply that some improvements in resident and staff satisfaction can be obtained without increasing costs or sacrificing avoidance of negative outcomes. It is unclear whether or not these ideas can be replicated across diverse facilities or whether or not variants of this approach can achieve social environment changes and improved outcomes across a range of care quality measures. The National Commission for Quality Long-term Care and others could promote implementation and comprehensive evaluation of alternative culture change models for nursing homes. Results from this kind of initiative could provide some of the information needed to inform policy in this area.

Long-Term Care Quality: Historical Overview and Current Initiatives

3. Continued Attention to OBQI

There is no denying the positive achievements associated with the current national framework for outcome-based quality improvement that includes well-tested measures of care process and outcome variation, dissemination of quality findings, and resources to support collaborative efforts to improve quality. Yet many analysts point with disappointment to the continued presence of quality deficiencies and remain concerned with the pace of adoption of state-of-the-art care processes. Several initiatives might be considered in this area.

- A. Holding states accountable for quality monitoring and enforcement: Although states are given responsibility by Federal law for monitoring the quality of care in nursing homes and other LTC settings, they are not being held accountable for the assertiveness strength of these efforts or achievement of overall quality improvements. New initiatives might explore either increasing the resources available to states for monitoring, enforcement, and collaborative improvement efforts, or transferring more of the monitoring and enforcement capacity to the Quality Improvement Organizations (QIOs).
- B. Organizational demonstration and research initiatives on accelerating adoption of quality process: Even with new information on performance relative to national quality of care indicators and availability of support from the QIOs, there has been uneven adoption by nursing homes of state-of-the-art care processes. Lack of adoption of these new protocols and technologies may simply reflect their relative novelty. New research initiatives are needed to understand how and why some nursing homes but not others are adopting new care protocols. Demonstrations of organizational change models that have been associated with adoption of innovations in other settings could be directed to nursing homes.
- C. Extension of current OBQI to Assisted Living: The assisted living market is inconsistently regulated across the nation, yet it is serving populations that at least partially overlap with nursing home residents in service needs and outcome trajectories. From a technical perspective, the OBQI framework could be readily extended to these settings. Such an extension, however, might require federal legislation that established national definitions and quality standards for assisted living. In the absence of federal action, individual states could be encouraged to enact their own standards for assisted living that include collection and reporting of MDS data and survey processes that parallel those for nursing homes.
- D. Exploring linkages among QI measures and care improvement initiatives: The current collaborative quality improvement efforts target single QI measures and associated processes. New research and demonstration efforts are needed to understand the linkages between QI measures and the process changes that can influence multiple outcomes.
- E. OBQI measures for community settings: We have described several of the factors that may limit the extension of the OBQI framework to community care, including: striking problems with accessibility of formal community care, absence of choice of providers and services in many communities, inadequate homecare workforce, intersection of formal and informal provision in these settings, and the central importance of patient autonomy and care satisfaction among community residents with LTC needs. Nonetheless, it may be possible to articulate some preliminary minimal standards for community care quality that focus on the kinds of glaring examples of unmet need that have been reported. While this approach cannot be expected to address the full range of unmet needs and poor care in the community, it might at least provide evidence about care for individuals and communities that would support quality LTC advocacy efforts.



Long-Term Care Quality: Historical Overview and Current Initiatives

Introduction and Overview

Quality has remained an elusive construct and a challenge for policy makers and others charged with providing, purchasing, and regulating long-term care (LTC). As in any healthcare context, LTC purchasers expect to be held accountable for making choices that best achieve their goals within resource constraints. Quality has also been viewed in terms of practices consistent with expert consensus about how to achieve specified goals. Formal LTC services meet needs associated with disability that are not met through the efforts of family or other informal caregivers. By contrast, elders whose health and socio-economic conditions require that they use LTC services can offer clear definitions of quality of care and quality of life. These elders and their families, nonetheless, find it difficult to locate services that meet their desires for quality care.

This report for the National Quality Forum explores the evolving definitions of quality LTC, the initiatives that have sought to improve quality, barriers to achieving this goal, and emerging opportunities to accelerate efforts to ensure that chronically ill and physically disabled adults have access to information that enables them to evaluate and compare LTC quality and to receive quality LTC. The types of LTC covered in this report include: nursing home care, skilled home health care, and home-based and community-based supportive care (called “community care” herein), and supportive housing settings such as assisted living. Because these settings sometimes serve children and persons of any age with mental retardation/ development disabilities, or chronic mental illness/substance abuse, much of this presentation has some relevance to these LTC populations. However, in most cases, these populations are cared for in separate service systems, financed through different approaches to reimbursement, and/or regulated by their own criteria, and in turn – different quality assurance and improvement approaches. Because of these differences, the National Quality Forum’s mandate for this initiative does not include providers, delivery, regulation, and financing systems that specifically target children and adults whose LTC needs are not primarily associated with aging-related chronic diseases and associated physical disabilities. Quality issues for mental retardation/ developmental disability and mental health/ substance abuse providers are not addressed in this report.

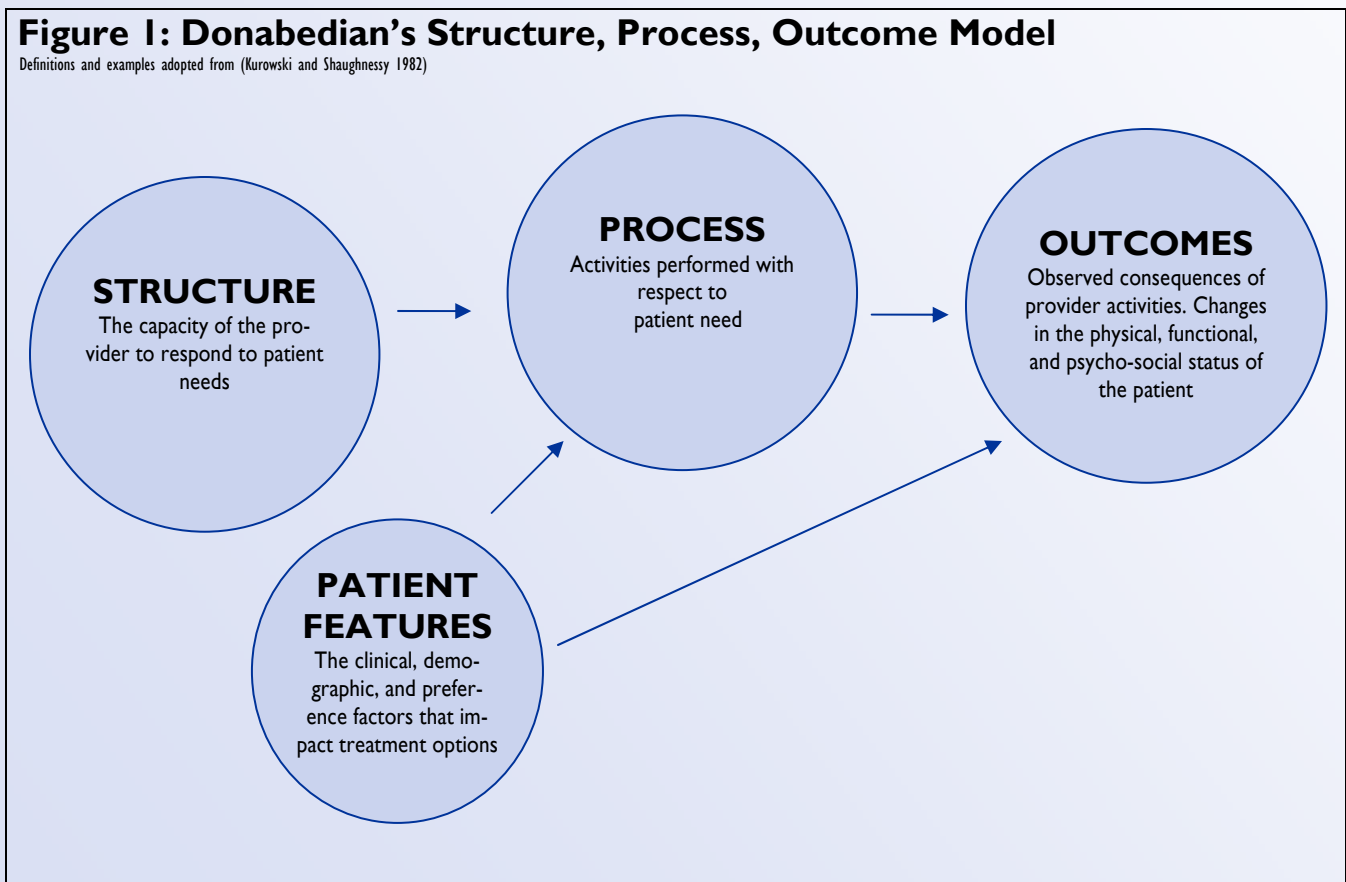
In health care in general, and in LTC in particular, the existence of multiple and shifting goals and concerns about LTC have kept debates about how to define and measure quality unresolved. In part this reflects the continual “raising of the bar”—establishing ever more demanding standards (from the fire safety concerns of the 1950s to the quality of care for pressure sores and pain concerns of today)—as a better understanding of LTC users and settings has emerged. At the same time, the shifting definitions of quality in LTC have been shaped by broader generational shifts in quality of life expectations among elders and their loved ones, changing demographics, and new recognition among professionals regarding the potential to improve the well-being of elders and others with the most severe disabling conditions. And always looming in the background – if not front and center – are the issues of cost and who will pay.

Quality needs to be understood within this context of evolving public policy goals for LTC. Rather than being a timeless absolute, quality is by its nature understood in terms of evolving public interests. As the likelihood of needing LTC has increased, so has the period of time that individuals survive with LTC needs. LTC has come to be viewed as both a challenge to health services financing and delivery, and as the defining feature of a significant phase in normal aging.

As the size and political power of LTC populations has grown, at least two strong traditions with respect to policy goals in this area have emerged (Capitman 2003). On one hand, LTC has been promoted as a mechanism to increase the cost-effectiveness of health care for persons with chronic disabling conditions by substituting lower levels of care (in terms of intensity, technological sophistication, or staffing requirements) for higher, more expensive ones. While this view highlights the importance of avoiding premature declines in function and other relevant health variables, it does not address the important goals of patient autonomy or patient perceptions of well-being. On the other hand, eldercare advocates and consumers of LTC services have tended to define policy goals in terms of their ability to ensure that elders or others with disabilities can maintain age-appropriate quality of life and community participation (Capitman 2003).

A consensus may be emerging to integrate these perspectives. Many would define policy goals for LTC as both supporting overall health system effectiveness by maximizing functioning and well-being for elders and others with disabilities within resource constraints, while also supporting the dignity of individuals with LTC needs and their informal caregivers by easing the financial and psychosocial barriers to self-determined quality of life and community participation. Quality LTC, from this perspective, requires that services help elders to attain the best possible health and functional status they can while enjoying as meaningful and “normal” a life as is feasible within public resource constraints.

We begin with an historical summary of efforts to improve the quality of LTC services in the United States. As detailed below, the general historical pattern in quality initiative in LTC can be characterized by three important shifts in focus. First, since the 1960s, LTC quality has been conceived by most using Donabedian’s framework that associates quality with structures, processes, and outcomes of care (Donabedian 1985). An application of this framework to LTC quality is shown in Figure 1. Significantly, the focus of attention has shifted over time from concern with basic structural factors such as fire hazards in facility construction) to process of care indicators (such as use of physical and chemical restraints) to outcome of care indicators (such as changes in functional status). The more recent increasing concerns with quality of life for LTC recipients can be viewed as an extension of this increasing focus on care outcomes.



Second, this period has seen a slow shift in the focus of public and private sector quality initiatives. In the early years, the focus was on the definition and measurement of quality aimed at sanctioning providers who failed to meet standards. More recently, total quality management (TQM) concepts have become more influential: quality initiatives seek to engage provider organizations in ongoing carefully monitored interventions intended to enhance care processes and improve care outcomes. Efforts to increase public awareness about quality expectations and performance are also part of this more current approach.

Third, attention has increasingly focused on defining quality at least partially with respect to participant autonomy in selecting and directing care. This conception has been a driving force behind the development of residential care alternatives to nursing home care, e.g., assisted living. Also, because many elders prefer to remain in community settings, quality is increasingly defined in terms of supporting this choice. With new attention to community care has also come stronger demands from regulators and consumer advocates to measure and ensure accessibility and quality of care in these diverse settings.

After examining in Section 2 how current initiatives have evolved, we look more closely at strategies focused on consensually defined outcome measures of quality and outcomes-based quality improvement approaches in Section 3. In Section 4, attention turns to barriers to achieving quality enhancement goals and opportunities for new initiatives. Recommendations follow in Section 5.

2. Historical Context for Long-Term Care Quality Initiatives

Concerns with the safety and quality of life experienced by elders and other persons with chronic disabling conditions have been at the center of health and social welfare debates since the 19th century. As growth in the size of both the LTC populations and the diverse private and public institutions and organizations seeking to meet the needs and preferences of these populations accelerated in the last half of the 20th Century, so have initiatives to promote quality services.

Each cycle of initiatives has addressed the most pressing problems, but each has left a new set of issues that were the unintended consequences of each solution. The challenge for quality improvement has been to move on to address newly identified problems – including problems spawned by the last set of reforms – without losing the positive features of those efforts and their forward momentum. This cyclical nature of reform for quality improvement must be recognized and addressed if improvements are to continue.

The cycles of quality issues and initiatives to improve long-term care quality have unfolded at different paces in institutional care, in housing-plus-services settings, in skilled home health care, and in community care. Across these settings, there are similarities and differences in these issues. We will deal first with the two types of residential settings where long-term care is provided and then turn to community settings. This historical section traces quality improvement efforts through the development and implementation of the Minimum Data Set (MDS) and current efforts to use it to evaluate and improve quality.

2.1 Quality Initiatives in Residential Care

Today's array of residential LTC facilities stem from several types of institutions developed in the 18th and 19th centuries. The earliest institutions were local poor houses, which operated from colonial times through the early 20th Century. Local governments and charities ran them as a last refuge for indigents among whom were significant numbers of elders and persons with disabilities. In the 18th Century, state governments developed hospitals for persons with mental illnesses and disabilities; and alongside these, numerous religious and ethnic groups built rest homes for their elders, as a more respectable alternative to the public institutions (Holstein and Cole 1996).

Major 20th Century events, particularly the Great Depression, eroded the capacity of these local, private, and state institutions to continue to operate as they had in the past. These events moved the nation, most notably in the Social Security Act of 1935, from local to state to federal responsibilities for income and care financing for elders. As a result, state and federal interest in and responsibility for ensuring and promoting quality also increased. Concerns began more and more to focus on creating an adequate supply of facilities, and on ensuring their safety through regulatory efforts.

The result of these efforts was to split residential care into two divergent paths. Down one path went unskilled residential care, including board and care homes and traditional old age homes. Down the other path went more regulated, skilled care institutions, more commonly known as nursing homes. We will follow the second path first and return later below to quality issues in unskilled residential care.

2.1 | Focus on supply, structure, and state regulatory capacity – the creation of the modern nursing home

Changes in the Social Security Act in 1950 allowed federal payments to the states to be used to contract with nursing homes for care for older adults and required states to create systems of nursing home licensing in order (according to the Act) to “raise the standards of those institutions that have been understaffed and underfinanced, that have been firetraps, and in which people have been badly treated.” States were also allowed to develop publicly operated LTC facilities as a result of these amendments. States were required by 1953 to assert an authority to establish and maintain standards for institutions receiving payments under the old-age assistance program. In the 1956 Social Security Act amendments, new funds were directed to the states to support home and community-oriented social services for elders and others with disabilities. Public expenditures for LTC grew dramatically during this period to about \$280 million by the end of the decade.

In 1954, the first national inventory of nursing homes and related facilities was conducted. The public debate about quality concerns noted in the survey was a factor in amending the Hill-Burton Act to treat nursing homes as health care facilities under the jurisdiction of the National Health Service, and to expand the availability of public financing for nursing home construction. According to Karen Stevenson Brown’s LTC history (Brown 2004), the Hill-Burton Act tied federal construction dollars to meeting quality standards but limited funding to a small group of non-profit organizations affiliated with hospitals. As a result,

....these standards had little impact on the vast majority of new nursing home construction. Ironically, restricting the funds to hospital-affiliated non-profits was intended to increase the quality of nursing homes, but it had the opposite effect. Developers who couldn't qualify for Hill-Burton funds continued to build thousands of new facilities with no reference to Hill-Burton standards. When regulators later decided that all nursing homes should meet the higher qualifications, it was too late. Trying to make the nursing homes fit the standards many years after they were built was nearly impossible.

Other expansions in federal financing for nursing home construction and nursing home care throughout the 1950s were also associated with continued concerns with the quality of care in these facilities. Well-publicized fires with high death rates and other traumatic events led to a national effort (1957-1963) to establish guidelines for states to adopt in licensing nursing homes. In 1959, a special Senate committee on problems of care for elders in LTC noted that the failure of states to adequately finance inspection protocols and implement quality assurance programming was a pressing concern. A 1960 Senate report claimed that as many as 44 percent of nursing homes failed to meet basic fire and safety standards (Brown 2004).

These concerns were a crucial factor in the passage of the Kerr-Mills Act of 1960, which offered states a higher level of matching funds for their expenditures on health care for indigent elders and extended support to the “medically needy.” Between 1960 and 1965, federal expenditures for LTC continued to grow, reaching \$690 million by 1965, with most of these expenditures concentrated in a small number of states whose guaranteed return on investment spurred private development of nursing facilities. But quality issues continued to receive public attention: a 1965 report by the Senate Select Committee on Aging noted that state regulation and enforcement of LTC facility quality was highly variable, but that increased enforcement could result in failure to meet escalating demand for these services.

Continuing concerns about the well-being and financial pressures faced by aged, blind and disabled persons using LTC facilities were a crucial element of the debates that led to establishment of the Medicare and Medicaid programs in the Social Security Amendments of 1965. The enactment of Medicare and Medicaid occurred in a highly charged political environment that led to a compromise limiting Medicare coverage for LTC to a new class of extended care facilities (ECFs) and for stays of less than 100 days, while the Medicaid program encouraged the states to offer both this level and a lower level of nursing home care to the indigent. States were given more flexibility in offering other services for the poorest elders and to the medically needy.

In the early years, Medicare expenditures for home health care services and ECFs far exceeded budgeted levels, because many more provider groups and facilities qualified for the program than anticipated, and cost-based reimbursement resulted in higher than anticipated expenditures. Meanwhile, the Medicaid program also experienced much higher than anticipated growth in expenditure for nursing home care. Brown notes at least four factors in this growth: (1) the Medicaid program did not provide coverage for community care services and thus created a perverse incentive for indigent and near-indigent elders to use more costly institutional services; (2) federal matching funds encouraged states to expand nursing facility coverage and to move people from state hospital settings, where states paid a higher proportion of costs, to nursing facilities, where states paid a lower portion of costs; (3) states were free to establish their own rates for nursing homes with no ceilings or caps imposed by the federal government; and (4) the federal government had inadequate fiscal controls or other data on utilization and costs within the state programs (Brown 2004).

Recognizing ongoing concerns with both costs and quality in nursing homes, the 1967 Moss amendments authorized the federal government to establish and apply fire and other safety requirements to all nursing homes participating in Medicaid and Medicare. These same amendments also established the intermediate care facility (ICF) category under Medicaid, although it took until 1971 to reach agreement on national standards for these facilities. These 1971 standards emphasized minimum fire safety and sanitary conditions, but also encouraged states to establish process of care and outcome objectives. Nearly 1,500 older facilities that could not meet these new standards closed between 1969 and 1971. This reflected the growing role of Medicaid as a monopsony buyer of nursing home services: by 1977, Medicaid was primary payer for 48 percent of all residents (Brown 2004).

2.12 Focus on process and outcomes of care in nursing homes

Notwithstanding improvements in supply, physical plants, and states' oversight capacities, reports on concerns with the quality of nursing home care and other LTC settings continued to appear throughout the 1970s (Mendelson 1974; Vladeck 1980). The "litany of nursing homes abuses" detailed in the 1974 Senate Subcommittee on Long-Term Care hearings emphasized the increasing technical sophistication and level of care in these facilities: Among the most common indicators of inappropriate quality conditions were lack of control of medications, inappropriate access to specialized and rehabilitative services, and unauthorized use of physical restraints. This focus on specific patient and condition-appropriate process of care and need-specific and case-mix sensitive outcome measures represented a major shift in focus for federal and other investigators from whether or not conditions were safe and sanitary to whether or not care maximized patient-specific outcomes.

Another set of conceptual shifts occurred during the 1970s which explicitly inserted roles for elder residents, their friends and other supporters in establishing and overseeing the quality of LTC services. For example, President Nixon's 1971 Eight Point Initiative to improve the quality of care in America's nursing homes and to respond to complaints about abuse and neglect of residents included a national Long-term Care Ombudsman Program. The President directed HEW "to assist the States in establishing investigative units which would respond in a responsible and constructive way to complaints made by or on behalf of individual nursing home patients" (Centers for Medicare and Medicaid Services 2002). By 1978 some consensus had emerged on how state units on aging would collaborate with other state agencies responsible for LTC facilities licensure or monitoring or as the payer for Medicaid-enrolled patients. A model set of requirements for a Long-Term Care Ombudsmen was included as a required feature of state aging services programming. The 1981 reauthorization of the Older American's Act explicitly expanded the roles of the program from nursing homes to personal care/assisted living and similar housing-plus-services models.

By the early 1980s, in response to public and professional concern that nursing home regulations placed undue emphasis on structure and process rather than the resulting outcomes, Congress directed the Health Care Financing Administration (HCFA) to study how to improve nursing home regulation. To perform the study, HCFA contracted with the Institute of Medicine (IOM), which established a committee on nursing home regulation. The IOM study team examined published literature and issued a landmark report that reflected a new consensus among a broad array of experts (Institute of Medicine 1986). The report's recommendations were reflected in the 1987 Omnibus Budget Reconciliation Act (OBRA).

The 1987 OBRA established new process standards for residents' rights, nurses' aide training, monitoring of psychotropic medications, and medical direction. It also directed the development of the Minimum Data Set (MDS) for resident assessment, which emerged and continues as a major data source for monitoring patient care and quality. The 1987 OBRA also required that facilities provide each patient with care that would enable the patient "to attain or maintain the highest practicable physical, mental and psychosocial well-being." Other concepts included:

- National minimum standards for staffing and nursing care for all Medicaid and Medicare nursing facilities, including 24-hour licensed practical nurse care seven days a week, and at least one RN on duty at least 8 hours per day, seven days a week.
- Elimination of the distinction between "Skilled Nursing Facilities" and "Intermediate Care Facilities" (both now defined as "nursing facility").
- Quality of life as a major goal for patients.
- Special training for nurse's aides.
- Requirements for states to establish and enforce state licensing and federal certification standards, including maintenance of an adequately staffed ombudsman program.
- A two-step approach to reduce inappropriate placements of people with mental illnesses/mental retardation in long-term care settings, which (1) restricts new admissions and, 2) requires a screening of all residents to determine most appropriate setting.

The evolution of current federal approaches to monitoring and regulating nursing home quality that began with the 1987 OBRA included the development of standardized resident assessment instruments (RAI) (which yields the MDS) and required assessment and reassessment protocols for all nursing facilities and all Medicare-certified home health agency patients. A series of demonstration projects, over a 5-year period, led to the designation of 24 quality indicators (QIs) for the federal nursing home survey process (Table 1). These QIs were designed to be a tool for capturing potential problems in performance that would flag certain facilities for additional inspection of quality. A number of the items are calculated on a risk-adjusted basis to reflect that incidence and prevalence are related to the characteristics of a nursing home's residents.

Unfortunately, despite this new national system of assessment, reporting, and regulation, nursing home quality problems continued through the 1990s. These included excessive use of physical and chemical restraints, untreated pain, poorly managed incontinence, and inadequate rehabilitation services. These were highlighted in a series of General Accounting Office (GAO) reports (U.S. General Accounting Office 1999; U.S. General Accounting Office 2000a; U.S. General Accounting Office 2000b; U.S. General Accounting Office 2002c; U.S. General Accounting Office 2002d; U.S. General Accounting Office 2002e; U.S. General Accounting Office 2003b), by additional startling documentation of ongoing quality failures, and by continued public dissatisfaction with LTC accessibility and lack of responsiveness to quality standards and public concerns. Research and analysis pointed to some basic shortcomings in the MDS and related enforcement activities underlying the problems, which will be detailed in Section 3. The remainder of this section describes federal and state efforts to expand and strengthen the MDS and related systems in the face of these continuing quality problems.

One major initiative beyond use of the QIs as indicators for improvement for individual nursing homes was to use the indicators for public reporting to help consumers evaluate and select nursing homes. In November 2002, the Centers for Medicare and Medicaid Services (CMS) began "Nursing Home Compare," a web site reporting individual nursing homes' scores on a related set of quality measures (available at: <http://www.medicare.gov/NHCompare>). CMS refers to the MDS-based indicators as "quality measures," asserting that they have been sufficiently validated to qualify as true measures of nursing home quality, as distinguished from the survey process QIs, which are to be used as pointers to potential quality problems that can be addressed by homes through the regulatory process. (This issue of distinguishing the use of indicators for quality improvement versus quality reporting will be elaborated in Section 3. Table 2 describes the nursing home quality measures that CMS reports for comparative purposes to the public. The web site provides, for each nursing home in the country, the scores for the individual home, the state averages, and the country averages in the noted categories. Bolded items in Table 2 indicate the measures that are the primary focus of state Quality Improvement Organizations' work with providers and the public (discussed just below). Table 3 provides background on why these bolded measures are important for quality.

¹ An analogous set of quality indicators for home health will be discussed below.

To reinforce the public use of Nursing Home Compare, the Department of Health and Human Services developed a new Quality Improvement Initiative (Centers for Medicare and Medicaid Services 2003). CMS contracted with its state QIOs to work with Medicare providers of nursing home and home health care services. These contracts are intended to raise public awareness of the availability of comparative quality data on Nursing Home Compare and at 1-800-MEDICARE.

The QIOs are also working with local media to publicize and explain information, as well as to promote quality information to those who assist elders in selecting services through collaborations with media, industry and consumer groups designed to promote use of the new measures.

At the same time, QIOs are required to work with nursing homes to improve the processes of care related to the publicly reported quality measures, particularly those noted in Table 3. As noted in the AHRQ National Healthcare Quality Report (Agency for Healthcare Research and Quality 2003), the focus in these contracts signals the shift in federal quality improvement efforts from a primarily regulatory approach, which mandates requirements for staffing or other inputs, to one which empowers consumers with quality data, while assisting providers in their efforts to improve performance on already established quality measures.

In summary, the federal government's 2001 Long Term Care Quality initiative included all the major components of quality assurance/quality improvement that have been emphasized in recent accounts:

Table 1: List of Quality Indicators: Version 6.3

Accidents

1. Incidence of new fractures
2. Prevalence of falls

Behavioral/Emotional Patterns

3. Prevalence of behavioral symptoms affecting others) [Risk Adjusted]
4. Prevalence of symptoms of depression
5. Prevalence of symptoms of depression and no antidepressant therapy

Clinical management

6. Prevalence of residents using 9 or more different medications

Cognitive patterns

7. Incidence of cognitive impairment two times in the last week

Elimination/incontinence

8. Prevalence of bladder or bowel incontinence [Risk Adjusted]
9. Prevalence of occasional bladder/bowel incontinence without toileting plan
10. Prevalence of indwelling catheters
11. Prevalence of fecal impaction

Infection control

12. Prevalence of urinary tract infections

Nutrition/eating

13. Prevalence of weight loss
14. Prevalence of tube feeding
15. Prevalence of dehydration

Physical functioning

16. Prevalence of bedfast residents
17. Incidence of decline in late loss ADLs
18. Incidence of decline in range of motion

Psychotropic drug use

19. Prevalence of antipsychotic use in the absence of psychotic and related conditions [Risk Adjusted]
20. Prevalence of antianxiety/hypnotic use
21. Prevalence of hypnotic use more than

Quality of life

22. Prevalence of daily physical restraints
23. Prevalence of little or no activity

Skin care

24. Prevalence of stage 1-4 pressure ulcers [Risk Adjusted]

(Source: Adapted from Manard 2002)

- Regulatory approaches: the federal and state governments establish standards, require documentation, inspect, and sanction deficiencies with respect to: (1) structure measures (staffing, resources, and environment requirements); (2) process measures (documentation using standardized instruments of care that minimally meets needs of residents); and (3) outcome measures (QI measures, such as documentation using standardized instruments of health and functional status patterns).
- Financial incentives/disincentives: Federal, state, and other public and private payers can establish financial incentives or disincentives that sanction/reward behavior as measured by any of the structure-process-outcome components.
- Empowered consumer decision-making: Broad dissemination of quality data on providers to support consumers, advocates, and group purchasers to foster the use of quality indicators in selecting and evaluating services.

Table 2: CMS Nursing Home Compare Quality Measures

Percent of Long Term residents:

- **Who have moderate to severe pain**
- **Who need help with basic tasks**
- **Who were physically restrained**
- Who are more depressed or anxious
- Who have a catheter inserted and left in their bladder
- Who spend most time in bed or chair
- **Whose ability to walk and move about their room got worse**
- **With a urinary tract infection**

Percent of high-risk Long Term residents:

- **Who have pressure sores**

Percent of low-risk residents:

- **Who have pressure sores**
- Who lose control of bowels or bladder

Percent of short-stay residents:

- **With delirium**
- **With moderate to severe pain**
- **Whose ability to walk/move about**

Table 3: CMS Measure Specifications for Nursing Homes

CMS Measure Specifications for Nursing Homes

<i>Quality Measures</i>	<i>Clinical Significance</i>
<i>For short-stay residents</i>	
1. Percentage of residents who improved in walking	Residents who stay in a nursing home for a short time are generally expected to improve their ability to walk so that they require little or no assistance in walking around their room.
2. Percentage of residents with delirium*	Delirium is a mix of short-term problems with focusing or shifting attention, or being confused. Delirium is a sign that the resident needs immediate medical attention.
3. Percentage of residents with pain	Residents in pain may become depressed or have an overall poor quality of life. In most cases, a resident in pain can be made more comfortable.
<i>For long-stay residents</i>	
1. Percentage of residents with loss of ability in basic tasks	Because most residents value being able to take care of themselves, it is important that nursing home staff encourage residents to do as much as they can for themselves. This includes feeding oneself, moving from one chair to another, and going to the bathroom alone.
2. Percentage of residents with infections	Examples of infections are pneumonia, wound infections, and urinary tract or bladder infections. Immunizations and other types of care can prevent certain types of infections. Infections can worsen the health of someone who is already weak.
3. Percentage of residents with pain	Residents in pain may become depressed or have an overall poor quality of life. In most cases, a resident in pain can be made more comfortable.
4. Percentage of residents with pressure (bed) sores*	Bedsore are skin wounds that usually develop on bony parts of the body. They may be painful and may take a long time to heal or cause other complications, such as skin and bone infections.
5. Percentage of residents in physical restraints	A physical restraint is any device, material, or equipment that keeps a resident from moving freely. A resident who is restrained daily can become weak and develop other medical complications.

*The quality measure for residents with delirium and residents with pressure sores is reported with and without an additional level of risk adjustment based on the conditions of residents that a facility usually admits.

In 1998, CMS contracted with Abt Associates Inc. to continue reviewing the QIs and to make recommendations to CMS on how its public reporting on nursing home quality could be improved (Abt Associates 2001). Using this work as a background, CMS asked the National Quality Forum (NQF) to identify a set of voluntary consensus standards for assessing the quality of care for both long-term residents and short-stay residents in nursing homes for the purposes of public reporting. As with all NQF consensus projects, the measures were evaluated by a Steering Committee and endorsed after successfully passing the vote of each member council and the NQF Board of Directors (which reflects a diverse group of health care stakeholders). Some of these recommendations were further considered, and additional recommendations were developed for voluntary quality standards. Since 2003, these standards have become the basis for subsequent CMS collection and reporting in its Nursing Home Quality Initiative.

Housing-Plus-Services Care

Having gone down the mainstream path traveled by institutional LTC in the US – the nursing facility – let us now return to the other path that institutional care took out of the Depression. This path leads to a variety of less formal and less regulated residential care, including board and care homes, traditional old age homes, adult foster homes, and more recently, assisted living facilities. The names for this level of care differ widely across states, as do the provisions for what kind of care they do and do not provide, as do the approaches to and intensity of state oversight. As a rule, housing plus services provide housing, three meals a day, and some level of support with supervision and help with activities of daily living (ADLs) – the latter perhaps for extra fees. For purposes of this report we will use the term “adult congregate living facilities” (ACLFs) to refer to all of these settings.

The ACLF path was also influenced by public policy decisions. The impact of public policy is readily apparent in legislative passed in 1935, when the Old Age Assistance of the Social Security Act included a provision that benefits would not be available to any person living in a public institution. This virtually ended the viability of any remaining local poor houses. The number of older people residing in institutions fell by 10 percent in the 1930s, then increased by 38 percent in the 1940s, stimulated by the resulting transfer of poorhouse residents to both nursing homes and private ACLFs (Holstein and Cole 1996).

Although nursing homes and ACLFs were not greatly differentiated before the 1950s in the types of care they provided, there are data that track the shift in residents from ACLFs toward nursing homes over the subsequent three decades. Of all elders residing in institutional settings, the proportion living in ACLFs shifted from 41 percent in 1940 to just 12 percent in 1970, while the proportion in nursing homes increased from 34 percent to 72 percent in the same period (Holstein and Cole 1996).

After this period of decline, however, the 1970s saw the beginning of new period of growth in ACLFs, stimulated by the widespread closures of state hospitals for the disabled, mentally retarded, and mentally ill (among whom were many elderly). The closures were in part fueled by the availability of Medicaid payment for housing and care in nursing homes, but not for care in state institutions. This period also saw increasing advocacy on the part of MR/DD, adult disabled, and mentally ill patients for care in the least restrictive settings. This advocacy became the basis for legal actions that reflected the view that the civil rights of these individuals were being violated by offering care in inadequate and restrictive hospitals. But not all of those leaving state hospitals went to nursing facilities. Many who were able to live more independently moved to ACLFs, with income support from Old Age Assistance, Aid to the Blind, and Aid to the Disabled. The federalization of these aid programs into SSI in 1971 increased support for the transitions, as did the ability of states to add supplements for ACLF providers for their SSI residents (Levine 1979; Palmer 1983).

Concerns and studies about the quality of care in ACLFs have paralleled the concerns about nursing home quality, but the response has not been as extensive or effective (GAO 1989; OIG 1982). For example, recent studies in board and care homes documented inappropriate use of physical and chemical restraints, a problem similar to those in nursing homes (Spore et al. 1997; Spore et al. 1995; Spore et al. 1996). Part of the difficulty in generalizing about quality in these facilities is that ACLFs are subject to state rather than federal standards, and there is wide variation at the state level in how states define ACLFs. There are also wide variations in what services and amenities states require and/or reimburse in the ACLF level of care. Some require personal care and others prohibit it. Some allow nursing care and help with medications, others don't. Some allow care managers and attendants to provide help to residents through Medicaid waiver services, and others don't. ACLFs also serve a wide market, from the low-cost SSI end to the high-cost, high-amenity “assisted living” end. But even in higher end facilities, overall staff-to-resident ratios are substantially lower than in nursing homes, so it is difficult to expect intensive or expert levels of nursing and personal care. And finally, for those facilities focused on serving the poor within revenue levels based on SSI and state supplements, staffing and amenities must be limited. Thus, the more disabled and medically complex are the residents of ACLFs, the more likely there are to be problems with quality of care (Feder et al. 1989).

The ACLF level of care has continued to grow. One study reports that between 1996 and 2001 the proportion of Medicare beneficiaries living in Medicare or Medicaid certified nursing facilities fell from 73 percent to 59 percent, while the proportion in “other” facilities jumped from 16 percent to 30 percent (McCormick and Chulis 2003). Hawes and colleagues conducted the most extensive recent study of ACLFs. They found that in 1998, there were 11,459 ACLFs nationwide, with 611,300 beds and 521,500 residents – about 1/3 the number residing in nursing facilities (Hawes et al. 2003). Most of the facilities were more than 15 years old, and nearly 3 in 5 were low-service, low-privacy, and relatively low-cost. These facilities need to operate within the limited level of funds available through SSI and supplements, e.g., for states supporting adult foster care in 1996, state SSI supplements ranged from \$62 per month in Iowa to \$690 in Maryland, on top of a maximum SSI payment in 1996 of \$470 (AARP 1996).

Much of the recent growth in the ACLF market has been in high-end “assisted living” facilities. Hawes’s study found that such high-end ACLFs offered more (e.g., nursing care and privacy), but were so expensive that they were beyond the financial reach of 84 percent of people over age 75 (Hawes, Rose and Phillips 1999). Research has found, however, that high cost and amenities should not be confused with quality. Yee and colleagues, for example, found that avoidable care problems were more likely to be found in high-price and for-profit facilities (Yee et al. 1999). Hawes and colleagues found that for residents who needed help with transferring, severe dementia, nursing for more than 14 days, or behavior problems, even high-end assisted living did not have adequate services to allow residents to age in place (Hawes et al. 2003). The IOM also gave mixed reviews to assisted living: some were found to combine home-like settings with high-quality care, while others did poorly on both counts. Also, the IOM concluded that consumers were not currently given enough information when choosing assisted living facilities, and that facilities were not providing appropriate care and could not consistently accommodate changing resident needs. For example, only 11 percent of assisted living facilities offered high levels of both privacy and care services (the two features that IOM identified as being the selling points of such facilities) (Institute of Medicine 2001).

2.3 Home Health Care

In this section, we discuss the historical development of quality initiatives in home health care. Although in the context of Medicare and current practice for other major payers, home health is viewed as a post-acute service or as a substitute for other acute medical services, quality initiatives in this area are relevant for understanding the state-of-the-art in LTC quality for three primary reasons: (1) people with chronic care needs and long-term disabilities disproportionately use these services, and (2) many of the paraprofessional home health services now offered are virtually indistinguishable from other paraprofessional home care, and (3) because home health services are offered in community, non-institutional settings, they may offer specific lessons for community-oriented LTC quality assurance. The historical development of efforts to improve the quality of home health care in the United States has largely paralleled the evolution of nursing home quality initiatives. The story starts with private efforts, which became more closely associated with other health care services, increasing public funding, and associated regulation. We follow the story through recent years, with the implementation of an outcomes-based quality improvement initiative by the Federal government, using an approach based on the MDS.

The first home health services can be traced to 1909, when the Metropolitan Life Insurance Company began offering coverage for home-delivered nursing services. This benefit grew in popularity and curative focus throughout the century (Speigel 1983). By 1953, home nursing programs were sponsored by leading hospitals and public health agencies nationwide, although concerns with the availability and quality of these services were being raised. Home health care was an established component of the health system by the time Medicare was enacted in 1965. Home health services under Medicare were covered when delivered by the new program for individuals who were confined to their residence, had services prescribed by a doctor, and needed part-time or intermittent skilled nursing service and/or physical or speech therapies. To be eligible for Part A coverage of these services, an individual needed to have had a prior hospital stay of at least 3 days. In 1980, the 3-day hospitalization requirement was dropped, and occupational therapy was added as a covered service.

The 1987 OBRA made important changes in quality assurance for home health agencies, by mandating state surveys of home health agencies using a standardized approach. Other OBRA components included (1) strengthening the rules governing participation in Medicare to require, for instance, that agencies hire only trained and competent home health aides; (2) requiring state or local agencies to maintain toll-free complaint hotlines; and (3) expanding sanctions to include options such as civil monetary penalties so that termination is not the only sanction available for home health agencies that fail to meet federal requirements. OBRA stimulated Medicare to take incremental steps from 1991 through 2001 to broaden the focus of surveys beyond a test of compliance with process requirements by including an evaluation of the kind of care being provided and the effect of that care on the beneficiaries being served.

In 1991, the Medicare program implemented a revised survey process using indicators of medical, nursing, and rehabilitative care to determine the quality and scope of patient care services provided by a home health agency. This approach was criticized because it continued to emphasize care processes over patient outcomes. While determining compliance with standard care processes is an important aspect of measuring quality of care, determining patient outcomes is also vital because it identifies the impact of poor care processes (U.S. General Accounting Office 2002b).

Following soon on the federal research and development effort for the nursing facility MDS, the government created a research and development program for improving data and quality monitoring in home health. This effort led to the Outcome and Assessment Information Set (OASIS) (Shaughnessy, Crisler and Schlenker 1998), which consists of about 80 data elements that form the core of a comprehensive assessment for home health patients and can serve as the basis for measuring treatment outcomes. Medicare home health agencies began collecting OASIS data in August 1999, and these data become a core part of the patient's clinical record. OASIS data were also used to develop Home Health Resource Groups (HHRGs), to which all home health patients are assigned to determine prospective payments to home health agencies.

OASIS data are also used by state surveyors along with other indicators to place patients into 80 distinct groups, using information gathered from assessments that home health agencies must perform at scheduled intervals to participate in Medicare. As the data became available, HCFA required state surveyors to access and review certain OASIS-based reports before conducting HHA surveys, including: (1) patient characteristics, (2) adverse events, (3) health care services utilization, and (4) improvement and stabilization of health status. These reports are intended to assist surveyors in targeting potential quality-of-care problems during the on-site survey and identifying individuals or types of patients to be included in the case-mix stratified sample.

Despite the new data and improved focus, problems remain. For example, a 2002 GAO report found that the design of the home health agency survey still allowed surveyors to cite a deficiency without addressing the patient outcome because the focus remained on care process (U.S. General Accounting Office 2002b). CMS now requires surveyors to use reports generated from OASIS data to focus survey activities on patients for whom quality of care may be a concern, but this change has not fundamentally altered the survey's reliance on process requirements to evaluate HHA performance. The same GAO report also noted other weaknesses in the survey process, such as the failure to survey agencies against all conditions of participation, and inadequate oversight of the branch offices of larger agencies. The GAO also reported that unlike the survey process for nursing homes, which uses a standardized framework to categorize quality-of-care problems identified during either standard surveys or complaint investigations in 1 of 12 categories according to their scope (the number of patients potentially or actually affected) and their severity, a standardized system does not exist in the HHA survey process. Although CMS had devoted considerable attention to increasing surveyor focus on OASIS data, this severity of deficiencies concept had not been introduced in the home health care survey process.

In 2002, the QIOs began using the OASIS data as the basis for a national initiative to help health agencies evaluate and improve their processes for delivering care. By October 2003, QIOs had trained three quarters of all Medicare-certified home health agencies to collect, analyze, and use information on quality of care and patient progress that is of practical value to clinicians. In that same year, CMS launched a web site, Home Health Compare, which publishes select OASIS findings on outcomes in home health care. The 11 quality measures for the Home Health Quality Initiative, listed below in Table 4, are a subset of a larger set of OASIS outcome measures. Building on positive findings from demonstrations, training activities include how to select areas to be monitored, how to plan to improve quality, and how to assess patient outcomes (Agency for Healthcare Research and Quality 2003).

While it is premature to assess the impacts of the introduction of outcomes-based quality improvement programming to Medicare home health care, it is important to note that Medicare home health quality is of direct relevance to larger concerns with quality of care for Medicare beneficiaries in need of LTC. Since its initiation, the Medicare home health benefits were not intended as LTC benefits, but rather as an effort to improve the cost-effectiveness of delivery of acute care services. Consistent with these goals, most elders with personal care limitations do not use home health in a given year (Feder, Komisar and Niefeld 2000).

Table 4: 11 Quality Measures for the Home Health Quality Initiative

Measure	Categories	Plain Language
Acute care hospitalization	Medical emergencies	Had to be admitted to the hospital.
Improvement in ambulation/locomotion	Getting around	Getting better at walking/moving around using less equipment.
Improvement in bathing	Meeting Basic Daily Needs	Getting better at bathing themselves/ without help.
Improvement in management of oral medications	Meeting Basic Daily Needs	Getting better at taking medicines without help.
Improvement in transferring	Getting around	Getting better at getting in and out of bed without help.
Improvement in upper body dressing	Meeting Basic Daily Needs	Getting better at dressing themselves without help (upper body).
Improvement in toileting	Getting around	Getting better at getting to or from the toilet without help.
Improvement in pain interfering with activity	Getting around	Having less pain when moving around.
Stabilization in bathing	Meeting Basic Daily Needs	Staying the same at bathing themselves without help
Improvement in confusion frequency	Mental Health	Confused less often
Any emergent care provided	Medical emergencies	Needed emergency medical care.

The Medicare home health participant population, nonetheless, is more like other LTC users than the bulk of Medicare participants: Home health users are more disabled and have had more expensive prior patterns of care (Hadley et al. 2000). Elders with disabilities have much higher Medicare payments, and this is at least partially true because of their much higher use of home health services (Chan et al. 2002). Further, home health services have consistently been utilized by participants in community care programs, and their availability is cited as a key factor in determining the both the outcomes and cost-effectiveness of these services (Capitman, Abrahams and Ritter 1997). The research showing that disabled elderly have poor access to ongoing community care, and that others leave home health with continued needs for personal care and household maintenance services (Thomas 1998), suggests that as is the case for community care services (discussed below), limitations on access or lengths of stay in home health can be viewed as a quality challenge.

2.3 Community care

Like institutional LTC, the origins of community care also stem from colonial times, when “outdoor relief” was provided as an alternative to the poor house for those without families to care for them (Holstein and Cole 1996). With 19th Century industrialization and immigration, however, outdoor relief declined. It became difficult to distinguish the “worthy poor” from those thought to be trying to avoid work. Willingness to endure the hardships of the poor house or the state institution became the test of need; family responsibilities were reinforced; and the availability of publicly supported care in home and community settings virtually disappeared until the 1970s, when nursing home scandals and lawsuits to close state hospitals awakened interest in alternatives to institutional care.

Initiatives to expand access to community care services were sponsored beginning in the mid-1970s by both Medicare and Medicaid, under research and demonstration waivers available in both programs. The quality issues addressed in these initiatives included not only improved access, but also the capacity of community care to avoid or delay institutional admissions, to reduce unmet needs for functional support, to improve functioning, and to increase satisfaction (Capitman 1989; Kemper, Applebaum and Harrigan 1987; Weissert, Cready and Pawelak 1988).

The desire to infuse new resources into community care, and to increase opportunities for community roles in managing LTC programs, were reflected in Section 2176 of the 1981 Omnibus Budget Reconciliation Act, which created broad waiver authority for states to develop community care programs under Section 1915c of the Social Security Act. The Medicaid waiver program also reflected the belief that expansion of community care could be primarily justified by the potential for downward substitution of community for institutional services and associated cost avoidance. Thus the waiver programs were expected to demonstrate budget neutrality and target services to individuals “who-but-for” the provision of community care would require Medicaid-reimbursed nursing home services.

The 1990s saw rapid growth in community care, as well as increasing attention to questions of quality in home health, other home care, adult day health, and community-based housing-plus-service providers such as assisted living facilities. By 2001, Medicaid community care spending had grown to \$14.4 billion and about 700,000 individuals (55 percent of them over age 65) were recipients of these services. But a 2003 GAO report found that, in the absence of specific federal requirements on states for measuring, documenting, or ensuring the quality of these services, the states had adopted highly varied approaches: access to appropriate levels of service remained a concern in many states, and available reports indicated the presence of sometimes severe quality gaps (U.S. General Accounting Office 2003a). Throughout this period, unmet needs among nursing home residents have been viewed as clear evidence that providers were failing to meet quality standards, but unmet needs within the context of community care have not received equal attention. The same period saw enormous growth in private expenditures for home-based services and the growth of assisted living and other housing-plus-service options.

The Medicare research on home health care, referenced above, also provides an important window into community care, which is often the next step for elders after skilled home health care. The studies show shortcomings in the capacity of skilled home health benefits to address LTC needs. For example, background research that led to the development of OASIS found that among those home health patients who had problems with each ADL, even the urban patients (who did better than rural ones), only 39 percent improved in bathing, 41 percent in feeding, and 27 percent in light meal preparation during their home health episode. Only 79 percent were discharged stabilized in bathing or transferring, indicating that large numbers of beneficiaries were being terminated from skilled home health with substantial unmet home care needs (Shaughnessy et al. 1996). Spurred by these findings, a number of efforts have attempted to define and measure the quality of care received by disabled persons in the community from the perspective of unmet needs (Allen and Mor 1997; Capitman, Abrahams and Ritter 1997)

Compared with home health care's OASIS system, quality initiatives in community care are less extensive, sophisticated, and organized. Initiatives and systems are state-based and tend to focus on structure and process, with emerging interest in patient satisfaction. Although there have been few studies, measures of satisfaction with care have been developed for various settings, such as paraprofessional home care (Geron et al. 2000), assisted living (Buelow and Fee 2000), and adult day health care (Henry and Capitman 1995).

A recent article is likely to spark interest in quality indicators derived from the MDS Home Care instrument and system (Hirdes et al. 2004). The quality indicators cover both process (lack of medication reviews, failure to receive flu shots) and outcomes (failure to improve or decline in ADLs), and they include risk-adjustment options using the larger MDS-HC data set. They were tested in Canadian and U.S. community care programs and purchasers, providers, and consumers could use them to assess and compare quality. While promising, the system is in its early testing phase, and its data collection and analysis requirements are beyond the current capacities of many community care programs and systems. Time will tell whether the instrument achieves a consensus on process and outcome measures appropriate to the diversity of community care providers and the interpenetration of formal and informal care in these settings.

3. Outcomes-Based Approaches to LTC Quality: Empirical and Conceptual Questions

As this historical summary reveals, the Outcome-Based Quality Indicators (OBQI) approaches to quality assurance, which foster collection and dissemination of standardized measures of health and functional status, complemented by continuing attention to structure and process measures, are now the mainstream approach to enhancing quality in nursing homes, home care, and even some community care venues. Yet researchers and policy analysts point to shortcomings in the underlying science and the coherence among established practices. Five sets of issues have received the most attention: (1) difficulty in consistently finding reliability and validity of quality indicators (QIs) in practice settings, (2) the validity of QIs as indicators of quality, (3) uncertain linkages among measures, (4) weak regulation in many states, and (5) questionable impacts of OBQI on care outcomes.

3.1 Validity and reliability in practice

Although the quality indicators used in the MDS perform well on formal reliability and validity tests, researchers have noted concerns about some specific types of indicators and the generalizability of these measures to actual practice settings. The 2001 IOM committee noted that reliability tests of the MDS are not generally conducted in "real world" circumstances, which may reduce confidence in studies about reliability. For example, there are some concerns that inter-rater reliability is too low in measuring the mood and behavioral status of cognitively impaired residents (Institute of Medicine 2001; Manard 2002; Ryan, Stone and Raynor 2004).

Since that IOM report, research has examined the relationships between facility scores on specific quality measures and actual care processes and patient outcomes in those areas of care. These studies compare facilities that have high and low scores on various quality indicators (for example, indicators for weight loss, pain, and incontinence) to determine whether the different rankings represent different care processes, and higher quality care for patients. In general, these studies find that there are few real differences in care processes between facilities that score well and those that do poorly on MDS indicators, and that in most cases the relationship between quality indicators and quality of care is too complex to be captured in the MDS (Bates-Jensen et al. 2003; Cadogan et al. 2004; Schnelle et al. 2004; Schnelle et al. 2003; Schnelle et al. 2001; Simmons et al. 2003). For example, Simmons et al. compared facilities that had high and low scores for MDS weight loss indicators. After assessing patient clinical status and care processes at these facilities, they concluded that these differences were more the result of the case mixes than of differing care processes. They noted that the staff at low-weight-loss nursing homes provided more interaction and encouragement to residents during mealtime than did staff at high-weight-loss nursing homes. These differences in care processes, however, were not revealed in MDS data (Simmons et al. 2003).

Research has also revealed that there may be perverse incentives and counter-productive conclusions drawn from MDS data and associated QIs. For example, one comparison of facilities that had high and low prevalence of pain found that residents in facilities with higher levels of pain prevalence were actually more likely to have been assessed by licensed nurses and physicians, received pain medication, and had documentation of treatment response (Cadogan et al. 2004). In other words, residents in high-pain-prevalence homes were more likely to have their pain assessed and treated appropriately than were residents in low-pain-prevalence homes. And, as Ryan et al. suggest in a review on the uses of the MDS, the better facilities are at measuring and documenting care problems, the more deficiencies those facilities may find (Ryan, Stone and Raynor 2004). Further complicating interpretation of rankings of nursing homes and home health agencies based on QIs are concerns that facilities are improving their paper compliance more than actually changing care processes (Ryan, Stone and Raynor 2004; Schnelle et al. 2003; Schnelle, Ouslander and Cruise 1997). Such studies raise concerns about the interpretability of OBQI ratings and rankings of various providers.

3.2 Use of QIs as indicators of quality

In addition to these limitations of the reliability of the OBQI measures, there are a variety of concerns about using QIs as measures of the quality of care. One area of concern is that direct comparisons of the raw rates of deficiencies across providers are inappropriate. As these scores represent aggregations of individual patient outcomes and developments, they are particularly sensitive to the case mix at a facility. For example, Jette et al. (1996) found that clinical characteristics of individual patients influenced the likelihood that quality of care deficiencies would be found.

Specifically, the more complex the care needs of an individual, the more likely that care deficiencies will be found (Jette, Smith and McDermott 1996). Similarly, Berlowitz et al. found that case-mix-adjusted facility rankings varied significantly from unadjusted facility rankings (Berlowitz et al. 1996). The two methods provided very different rankings of facilities, and case-mix-adjusted rates came closest to a gold standard of individualized assessments based on extensive patient clinical information (Mukamel and Brower 1998). Therefore, even though many support the use of MDS outcome-based data for internal quality improvement at a given facility, the use of the MDS data for ranking and comparing facilities is still controversial (Mor et al. 2003b; Ryan, Stone and Raynor 2004). The literature does not fully address whether case-mix-adjusted or unadjusted rankings are the most representative of actual patient care, although work is being done in this area (Manard 2002; Mor et al. 2003b; Ryan, Stone and Raynor 2004).

While much attention has focused on defining, choosing, and validating quality improvement measures (Mor 2004; Mor et al. 2003a; Zimmerman et al. 1995), little literature currently exists that directly links the implementation of MDS to patient outcomes and satisfaction.

Hawes and colleagues reported that as a result of Resident Assessment Instrument implementation and OBRA-mandated changes, nursing home care improved overall, especially with regards to the reporting of patient information, the accuracy of medical records, and comprehensiveness of individual care plans (Hawes et al. 1997).

But these results are controversial (Schnelle, Ouslander and Cruise 1997). Several studies assessed the relationship between MDS participation and reductions in specific negative outcomes, including pressure ulcers, use of antipsychotic drugs, and restraint use (Berlowitz et al. 2000; Schnelle, Ouslander and Cruise 1997). For example, Coleman and colleagues compared rates of pressure ulcers in two time periods: 1992-1994 and 1997-1998 and found no statistical difference in the rates even after risk adjustments (Coleman et al. 2002). Overall, the comprehensive IOM review concluded that the clinical impacts of the changes in pressure ulcers, restraint use and other quality indicators since the implementation of MDS have not been well documented (Institute of Medicine 2001).

Simple conclusions about quality of care based on QIs are also difficult because it does not appear that facilities that do well on one measure do similarly well on other measures (Porell and Caro 1998). There is therefore no overall measure of quality of care, and rankings rely on the aggregation of the number of deficiencies that a facility receives. Because facilities vary dramatically in their overall quality rankings based on the measures included, some have argued that this method is too subject to the whims of particular compilations of key measures and that there is no way of determining which deficiencies or successes are more indicative of overall quality.

Barbara Manard offers a conceptualization of the purposes of quality measurement and monitoring that is helpful in sorting out the legitimate but conflicting types of information needed by different participants. Her formulation – summarized in Table –5—reminds us that how we wish to use a measure of quality informs its ideal characteristics (Manard 2002). The table summarizes the distinction between developing measures of quality for use in quality improvement initiatives and measures of quality for public accountability. Quality improvement interventionists want quick turnaround data that are sensitive to small changes in resources and practice, while those concerned with public accountability are seeking global information to support decision-making based on larger, reliable samples, with findings relevant to diverse audiences.

The CMS nursing home and home health QIs, rather than fitting neatly within the categories of process and outcome, or reflecting exacting science about the most parsimonious indicators of conditions likely to maximize health and well-being across diverse LTC populations, appear to address both accountability and quality improvement goals.

Table 5: Comparison of Quality Measurement for Quality Improvement versus Public Accountability
(Adapted from Manard 2002)

Issue	Measurement for Quality Improvement	Measurement for Public Accountability
Purpose	Identify process to be improved, or test results of efforts	Purchase decision, evaluate programs and policies, or conduct needs assessments
Requester/ Audience	Internal (e.g., staff, providers, or managers)	External (e.g., purchasers, accrediting bodies, regulators, policymakers)
What to measure	Biggest gap between practice and science.	Measures with wide public acceptance or importance
Frequency of Measure	Very frequent (weekly)	Less frequently (e.g., annually)
Comparison	Longitudinal within facility or unit	Cross-sectional and longitudinal
Sample size	Often relatively small	Large samples.
Detection of bias	No audit, measurement done internally	External audit and/or external measurement required
Level of sophistication	Simple, not likely to be challenged	Appears simple, but rigorous and defensible
Level of detail	Very specific, miniscule	Summarized, global
Expected response	Behavior change	Decision making

While CMS and others may be entirely justified in selecting certain indicators as prima facie evidence for high quality of care, they may be unduly limiting attention and interest in finding finer and more closely calibrated measures of more diverse and dynamic expressions of quality. The uncertainty of the exact linkages between LTC provider resources or behaviors to long-term care recipient outcomes has also led to efforts to blur the distinction between measures of specific quality indicators and overall policy-relevant outcome measures.

3.3 Uncertain linkage between measures

It has also been difficult to demonstrate the expected impacts of structural and process quality dimensions on health and functional status or quality of life outcomes. Kurowksi and Shaughnessy (1982) emphasized this point 20 years ago, and it has been demonstrated in more recent papers. The structure-outcome relationship has received the most attention. For example, early studies showed that having nursing home capacity to deliver social services or specialized rehabilitation did not predict provision of these services or relevant outcomes. This is because capacity alone does not indicate whether or not a functioning and correctly targeted program is in place. Very specific measures of process (forced fluids, for example) were linked to very specific outcomes (rates of dehydration), particularly in the short run, but generalization from appropriate process indicators to comparable care processes or more distal outcomes (as might be implied by a quality indicator interpretation of process or outcome measures) proved problematic (Kurowski and Shaughnessy 1982).

More recent studies show continued difficulties in linking process and outcomes, except when the measures are conceptually closely tied. For example, Harrington et al. found that nursing home staffing levels were unrelated to process measures of care quality derived from MDS (Harrington et al. 2000). But Weech-Maldonado and colleagues suggest that staffing has a more complex relationship to outcomes, based on the kinds of knowledge that different professionals can offer (Weech-Maldonado et al. 2004). They used MDS-derived quality of care process and outcome measures and found that having more registered nurses on staff was associated with improved outcomes of care, while having more full-time nurses was associated with improved process as well as outcomes of care. This finding may be consistent with the conclusions reached by Abt Associates in a multi-year study of nursing home staffing levels and patient outcomes (Centers for Medicare and Medicaid Services 2002). They concluded that increased staffing intensity is associated with better patient process and outcome measures up to a certain point, but that staffing increases beyond these minimum levels have little effect. Most nursing homes would need to increase staffing to meet the minimum staffing levels as calculated in the Abt reports. Notwithstanding these findings, they did not recommend increases in national staffing level requirements because of concerns with measurement of staffing levels, labor shortages, and increased costs for public payers. A recent study from Finland adds some new perspective to these findings. Both employees' and relatives' assessments of quality were related to stress and time pressure on workers. Pressure was related to greater needs among residents and larger unit size.

In summary, the failure to link nursing home structure measures to process and outcomes measures of quality may say more about the variations in nursing home resource levels and services that are considered acceptable than the underlying theory: structure and process measures may not have strong links to the most general outcome quality indicators because professional and regulatory standards keep services within a narrow range. Simply adding more resources within narrow limits may not change the care delivery model.

3.4 Continuing gaps in regulation

Despite emergence and subsequent development of the OBRA 87 framework for ensuring the quality of nursing home care, the period since its implementation has seen both continued dissatisfaction with the regulation and management of nursing home quality and continued attention to quality issues in other LTC domains. A series of GAO studies have examined the adequacy of nursing homes, home health care, and community care from the perspective of care process and outcomes indicators.

In reports throughout the 1990s, and as recently as 2003, the GAO found that state processes for monitoring and ensuring the quality of care in nursing homes and other settings were inadequate (U.S. General Accounting Office 1999; U.S. General Accounting Office 2000a; U.S. General Accounting Office 2000b; U.S. General Accounting Office 2002b; U.S. General Accounting Office 2002c; U.S. General Accounting Office 2002d; U.S. General Accounting Office 2002e; U.S. General Accounting Office 2003a; U.S. General Accounting Office 2003b).

The GAO reports noted improvements in basic safety and sanitary conditions of nursing homes, but they also found high levels of potentially dangerous conditions and practices for residents that were being missed or insufficiently noted in existing state regulatory processes. For example, the 2003 report found that during the 18-month period, from June, 2000 to January, 2002, more than 20 percent of the nation's 17,000 nursing facilities had deficiencies in care that could be gleaned from MDS reports (U.S. General Accounting Office 2003b). Highlighted as reasons for high rates of deficiencies were relatively limited state budgets for inspections, high turnover and inexperience among inspectors, and inadequate systems for working with nursing homes to address existing problems.

More generally, the 2001 IOM report found scant evidence that regulatory standards, clinical information systems and practice guidelines are really solving quality problems in nursing homes and noted that these guidelines are not currently implemented routinely or effectively (Institute of Medicine 2001). They concluded that staffing limitations and weak management systems prevent homes from fully implementing outcome-based quality improvement programs or even effectively collecting and evaluating data. These factors severely limit potential applications of MDS data and make testing the full, potential utility of the dataset difficult.

3.5 Linking measurement to practice

Findings from GAO and others underscore the difficulties in moving from outcomes-based measurement of quality to real-world enhancements in quality. Simply put, sharing data on relative OBQI performance with providers does not necessarily lead to improvements in care processes. Recognizing this, QIOs, states, and clinical research teams have embarked on collaborative approaches to quality improvement: provider staff teams work with quality improvement experts to identify strategies that they can implement first to reduce quality deficiencies (compared with other providers), and then to track the relative outcome measures. In this context, like other technology-transfer specialists, they have been influenced by the Chronic Care Model (Wagner, Austin and Von Korff 1996).

Wagner and others have offered a heuristic framework for characterizing the level of adoption of mechanisms and resources to support high-quality service provision. From this perspective, care improvement begins with the selection by a health care organization of practice guidelines, followed by team decision-making on adaptation of these guidelines to the particular setting through a protocol that states explicitly what needs to be done for which patients, when and by whom. This protocol generally includes the practice/delivery redesign (practitioner and other staff roles), collaborative management (educational/self-management support for service users; active follow-up procedures), decision supports for practitioners (provider education, feedback, consultation, referral resources), and clinical information systems (registries, reminders, outcome tracking, procedure codes for billing). This framework implies that adoption of recommended LTC care processes cannot be defined as a group of dichotomous variables but as consisting of an aggregate set of specific changes in practice/delivery systems and the development of resources to support patients (and their families) and practitioners/site managers in continued implementation.

CMS and others have pointed to process and outcome improvements that have occurred through implementation of many of steps in the adoption of healthcare innovations. The literature includes interventions with significant positive impacts on the QIs related to overall patient outcomes (Allen et al. 2004), pressure ulcers (Baier et al. 2003; Wipke-Tevis et al. 2004), and depression (Boyle et al. 2004). In all of these cases, the observed changes, while significant, were modest; their costs have not been assessed; and long-term impacts on patterns of care in the participating facilities were not described. No published studies describe the generalization of changes in care process to other areas of quality within the participating organizations.

Further examples of the potential impacts of the collaborative approach to improving home health agency and nursing home performance on specific QIs are offered by the American Health Quality Association (AHQA), the industry group for QIOs, based on its tracking of member organizations and their initiatives. Figure 2 summarizes some of the success stories they document. The AHQA finds that the QIOs in each state have adopted different priority QIs and different strategies for working with subsets of the providers in their states or a handful of provider organizations (AHQA 2004). Yet as pointed out by Schnelle et al. (1997) these examples all involve relatively high levels of engagement by provider organizations. Schnelle et al. found that levels of adoption varied notably across providers even in the context of collaborative efforts (Schnelle, Ouslander and Cruise 1997). Berlowitz et al. (2003) also found broad variations across organizations in consistent application of new practices. Sites with greater levels of staff satisfaction and a culture that promoted innovation were notably more effective in altering practice patterns (Berlowitz et al. 2003).

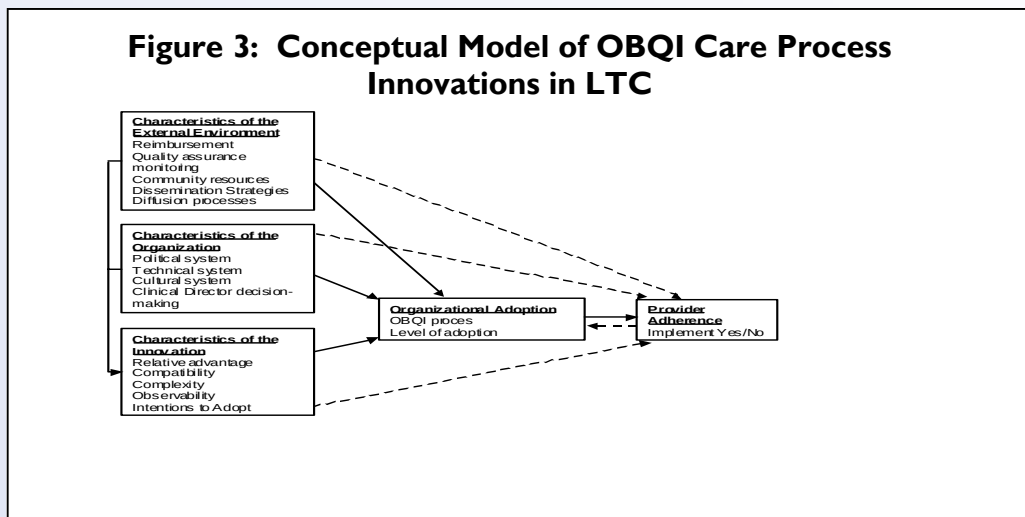
These findings suggest that the collaborative approach to promulgating state-of-the-art caregiving processes in LTC can be viewed in light of the larger literature on diffusion of healthcare innovation. Earlier models of diffusion of innovation in health care tended to focus on the factors that lead individual physicians and other practitioners to begin using a new technology, but they were based on a model that largely ignored organizational determinants of adoption (Rogers 1983). More recently and particularly in the case of preventive and chronic care services, organizational adoption of innovation is viewed as an important influence on individual practitioner attitudes and behavior and as strongly influenced by the attitudes of clinical leaders towards the new technology (Epps et al. 1998; Glasgow, Lichtenstein and Marcus 2003; McCarty et al. 2004; Thomas et al. 2000; Thomas et al. 2003). Thomas et al. (2000) note the importance of explicit federal and private initiatives to develop and diffuse adoption of preventive health strategies to health care providers as representing a distinct set of influences on adoption and implementation that deserve special attention. Figure 3 shows an adaptation of the Thomas et al. (2000) model to LTC process quality initiatives. Understandings of how these elements combine in creating a context for full adoption of the recommended process improvements to achieve desired quality outcomes.

Figure 2: AHQA Examples of Response to OQBI*

Woodland Park Care Center Reduces Pain For Residents	High pain measure scores spurred the staff to initiate education in pain management and how to treat specific types of pain. Through collaboration with the medical director, they developed a Pain Team and created a tool to assist nurses with assessment and treatment of pain. The percentage of residents with pain has decreased from 24% to 5%.
White County Medical Center Home Health, Searcy, AR, significantly improves care for surgical wounds	The agency increased improvement of surgical wounds to 74% in early 2003 from 56% in 2002. They established a wound care committee of home care and hospital staff, new wound care protocols, and staff training. These changes required multidisciplinary staff participation, new quarterly reporting, and training of new staff.
Chestnut Hill Convalescent Center, Passaic, NJ, reduces pressure ulcers by almost 50%	An interdisciplinary team was formed to direct a facility-wide effort, examine tools and encourage the involvement of all staff. They purchased special mattresses for residents and created a program that enhances aides' commitment to the reduction of pressure ulcers, including completion of daily flow sheets, monitoring of residents by staff on all shifts. Staff use a pressure ulcer and wound tracking tool and skin assessment check sheet that is completed by Certified Nursing Assistants and reviewed by nursing staff.
Heritage House, a nursing home in Clinton, IN, improves care for diabetes:	The facility improved its rate of HbA1c testing of blood sugar for diabetes from 45.0% of residents at baseline measurement, 2001, to 83.3% at the completion of a targeted intervention in 2002. They sponsored diabetes education, and development of more effective policies and procedures for diabetes care. Physicians, nurses and providers were also educated about diabetes consensus guidelines, pertinent journal articles, diabetes web sites, and diabetes care and management.
Oregon's Rogue Valley Home Care and Hospice improves treatment of pain:	The agency measures of reducing pain to acceptable levels within three days improved from 75% to 87%, above the national average. A pain management team was developed and instituted an action plan which included: changing home visit notes to remind staff to use best practices in pain treatment; developing a "bathroom newsletter" to keep staff apprised of quality improvement efforts, creating a reminder system during staff meetings, and developing "pain competencies," which involved presenting staff with pain scenarios to work through with guidance on selection of pain reduction methods and procedures.
Home Recovery Home Health, a home health agency in Farmville, VA, decreases the number of patient surgical wounds by 48 percent:	The agency plan of action to decrease the number of patient surgical wounds included development of best practices guidelines adoption, new documentation expectations, and patient/caregiver education requirements. The agency moved from 50% to 73 % in decreasing the number of their patients' surgical wounds over a 12-month period.

*Source: American Health Quality Association web site:
http://www.ahqa.org/pub/media/159_766_4627.CFM#homecare

In reviewing the evidence of the collaborative approach being used to improve LTC performance on QIs, it is clear that studies to date have considered only some of the factors associated with adoption of innovation, including some characteristics of the innovation itself, some characteristics of the LTC organizations, and some aspects of the external environment. For example, quality improvement programs require the capacity to collect and handle complicated information systems, which most nursing homes do not have (Schnelle, Ouslander and Cruise 1997). None of the existing studies address how facilities would operationalize the information technology demands of implementing multiple OBQI initiatives. Similarly, Eaton notes the limits of staff education efforts in improving quality without also redirecting management to support care process changes (Eaton 2000). As work proceeds in this area, we will need better understandings of how these elements combine in creating a context for full adoption of the recommended process improvements to achieve desired quality outcomes.



4. Barriers to Quality Improvement in LTC

Reading the literature on quality improvement in LTC feels at times like an exercise in futility. In nursing homes, our current regulations (focused on inputs and assessments of adverse outcomes) have improved quality in measurable ways (e.g., less use of restraints), but experts do not think they do a good job distinguishing good homes from bad homes, or in helping homes get better. Moreover, improved outcomes in LTC have been harder to define than in acute care, so the focus has been primarily on avoiding bad outcomes: none of the demonstrations of the collaborative outcomes-based quality improvement approach have focused on fostering higher levels of functional status improvement or similar positive outcomes. Again and again the literature finds promise in innovative models, protocols, and practice guidelines for “best practice” care for certain conditions. In trials these guidelines are generally found to be helpful, but then the new practices are not even able to survive in the test homes, let alone be more widely implemented (Institute of Medicine 2001).

The situation in home and community care is in some ways worse and in some ways better: worse because there is much less commitment to even a minimum standard of access and quality, but perhaps better from a firmer acknowledgement that quality of life and choice may be appropriate first-order goals for LTC quality initiatives. The “worse” aspect stems from the fact that there is no national community care program—even for the poor—and the infrastructure for a community care program is missing in most states. Absent a core program, the IOM finds no alternative to recommending extensions of OBQI based on uniform data collection and monitoring for community care and assisted living, even though no consensus has been achieved on defining process and outcome measures of quality care for these settings (Kane et al. 1994). Particularly uncertain, in this context, is how the emerging quality goals related to patient autonomy and quality of life can be accommodated in this model: available studies do not suggest that the experience of loss of autonomy among patients who do not wish to be in a nursing home, for example, can be mitigated by permitting them more choices with respect to facility protocols (Capitman and Sciegaj 1995).

From this perspective, increasing the efficacy of OBQI approaches represents not only a technical challenge, but also a challenge to our national will and values in caring for elders with disabilities. What may be standing behind the various barriers to change is the way the U.S. values Medicaid nursing home patients, both explicitly (seen for example in reimbursement rates and caregiver salaries) and implicitly (seen in the spend-down requirement and welfare stigma attached to Medicaid as well as a problem-avoidance approach to quality). The result is something akin to stigmatization of the nursing home population and appears contrary to the goal of ensuring quality of life for program participants.

The remainder of this section describes specific barriers to quality improvement in LTC. We deal in turn with barriers to quality in nursing homes, community care, and housing-plus-services settings. We conclude with a discussion on market barriers. But first we begin with a barrier common to all settings: personnel.

4.1 Personnel: A common barrier to improving quality

For at least a decade researchers have been concerned with the problem of LTC worker shortages (Crown, Ahlburg and MacAdam 1995; Institute of Medicine 1996b; Institute of Medicine 2001). Because of the nature of long-term care worker positions as low-wage, low-benefits, high turnover and poor working conditions supply shortages in this market occur frequently, and are especially severe when the economy does well (Feldman 1996). Working conditions in LTC settings are also significantly poorer than conditions for the same types of staff in acute care settings (Crown, Ahlburg and MacAdam 1995; Feldman 1996). Problems with home care worker shortages are a particular problem. One report notes that some states have developed task forces to deal specifically with the shortage in home care workers (Institute of Medicine 2001). Home care workers tend to be overwhelmingly female, nonwhite, and have low educational levels (Crown, Ahlburg and MacAdam 1995; Institute of Medicine 1996a). These workers are also the least well paid when compared with health aides in hospitals and nursing homes (Crown, Ahlburg and MacAdam 1995). Even full-time workers in the home care industry have incomes that are barely above poverty. Very few workers enjoy benefits such as health insurance, pensions, or sick or vacation pay, and most have irregular hours of work. All of these factors make the concerns about high turnover and frequent shortages in worker supply particularly potent for the home care industry.

The IOM committee cites four factors to explain the low wages and benefits that characterize employment in the LTC sector: the limitations of Medicare and Medicaid reimbursements, a high reliance on self-paying patients with limited financial resources, the profit orientation of many providers, and barriers to unionization (Close et al. 1994; Institute of Medicine 2001). This problem with care worker shortages is likely only to worsen as the number of people needing home care increases relative to the workforce population. The IOM 2001 quality report cites a Bureau of Labor Statistics projection that jobs in the LTC sector will increase 53 percent between 1996 and 2006 (Institute of Medicine 2001). Further, care previously done by informal workers may now require formal caregivers because of changing demographics (lower marriage rates, families living farther apart), and because tasks able to be performed at home are more technical or require more training and were previously the domain of medical or technical professionals (Institute of Medicine 1996a). In addition, quality improvement efforts often rely on increased staffing, more training for staff, and the increase of available services, all of which will increase demand for LTC workers.

4.2 Nursing home barriers

Four sets of barriers to improving nursing home quality may be identified: medical/regulatory conceptualization of quality, inadequate resources, technological limits, and lack of clear impetus for change. These are described below.

4.2.1 The medical/regulatory concept of nursing home quality

The MDS and associated monitoring and reporting systems have been an important step forward from where we were prior to the 1987 OBRA. A tremendous amount has been invested in the MDS, and it has proven to be a way to set national and even international standards to monitor and protect against the return of the low and uneven quality of 20 years ago.

However, the protective, medical, and regulatory approach of the MDS system is also widely acknowledged as a barrier to an expanded OBQI model that includes attention to patient autonomy and quality of life. What was a progressive way to address abuse and neglect 20 years ago seems now at times to stand in the way of newly prevailing values about what nursing home residents need. The focus on accountability and on minimizing selected adverse outcomes makes specific tasks and avoidance of mistakes the focus of facilities, rather than the needs and wants of the individual people in their care. Rosalie Kane gives one of the clearest expressions of the dilemma: “Embedded in most of our rules and regulations is the idea that LTC should aspire to the best possible 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 2001a, italics in original).

A review of the literature on the most important resident-reported features of quality of life reveals the centrality of concepts such as autonomy, choice and control, and personal meaning. Even though these same themes appear again and again in resident ratings of quality of life, these themes are often not brought into OBQI interventions in LTC (Institute of Medicine 2001; Salmon and Polivka 1998). There is good work moving the quality of life agenda along, but it has a ways to go (e.g., Levy-Storms, Schnelle and Simmons 2002). For example, if an individual chooses a care option or activity that puts his or her physical safety at risk, how is the provider’s responsibility for promoting safety modified? If a goal of LTC is rehabilitation, how can the provider balance the wishes of a patient who chooses not to work at recovery? In addressing these questions, Capitman and Sciegaj have suggested that the goal in LTC is not so much autonomy, as classically defined with its focus on independent actors, broad opportunities for self-definition, and culture-free decision-making process, but rather a “contextual autonomy” which emphasizes engaging elders and their social networks in culturally-responsive decision-making based on full disclosure of the provider’s limitations and professional/corporate obligations (Capitman and Sciegaj 1995). From this perspective, the resolution to Rosalie Kane’s quality/safety dilemma and similar challenges arises from an explicit negotiation with full disclosure among providers, patients, and patient families as they seek to find quality of care and quality of life that respects individual preferences and resources, but without sacrificing provider commitment to maximizing positive health outcomes.

4.22 Technology barriers

Stalling the resolution of the conflict between quality of life and quality of care objectives in LTC are current technologies and organizational arrangements that limit the capacity to implement and manage individualized services. No quality model has research that points definitively to its efficacy (Wiener 2003). The OBQI approach has clearly achieved successes in getting many organizations to make some important changes (e.g., use of restraints), but has been only modestly successful in a few organizations for other care processes (e.g., pressure ulcers). The standardized systems of measurement do not have the capacity to acknowledge excellence in care (such as, maximizing physical functioning) (Institute of Medicine 2001). In fact, as shown above, the MDS and survey measures of structural or process deficiencies do not consistently distinguish between good and bad homes according to expert assessments. This suggests that reaching OBQI targets does not necessarily equate with good quality or that missing them equates with bad quality. From a purely technical perspective, introducing more adequate adjustments for case mix, including selectivity in entry and exit from homes (Mukamel and Brower 1998), would increase the sensitivity of these measures to real differences in care quality.

Better models for separating out the relative importance of staffing, resident characteristics, and facility characteristics as contributors to deficiencies would also be helpful (Harrington et al. 2000). But these improvements don’t address the capacity of facilities to individualize care in ways that respond to the elderly’s and their families’ preferences for quality of life.

Measuring quality of life has its own challenges. We have been able to find only one example of a study that demonstrates whether or not satisfaction with care or quality of life outcomes are correlated with QI measures or whether systematic efforts to improve care process to influence quality also influence satisfaction or quality of life outcomes. The one study is not encouraging: Schnelle and colleagues found that nursing home residents and their families who received more appropriate and frequent care for selected conditions did not rate their quality better than did others who received inferior care (Schnelle et al. 1999). The lack of data in this area, however, reflects the lack of consensus on how best to measure these outcomes in the context of nursing home care or other LTC settings, characterized by the high prevalence of cognitive impairment and other health and functional status changes that may limit both the range of satisfaction/quality of life outcomes and the capacity of individuals to report on them. Robert Kane, for example, points to the difficulty in capturing the essential elements of a subjective measure in a way that will mean the same things to everyone; difficulty developing measurements that can reflect all the domains of quality of life; and the difficulty determining the relative importance of different domains to different people (Kane 2001b).

The 2001 IOM report contends that general “satisfaction measures” have limited value since overall satisfaction is reported as high. Such measures miss serious deficiencies in individual areas. Since many residents lack knowledge about what could ideally be done for them, they lower their expectations and are not sufficiently critical (Institute of Medicine 2001). Hays attempted to address this issue through the creation of weights for quality of life measures for nursing home residents (Hays et al. 1996), but this approach may not adequately respond to individual and cultural differences in response styles or the disentangling of health and functional status linked affective changes from variable preferences.

There are some new approaches in the pipeline. According to the IOM, one major attempt at developing a standardized tool for measuring resident-reported quality of life was REAL (Real Experiences and Assessment of Life). The REAL instrument was composed of Yes/No questions to residents about various aspects of life in the nursing home and was developed by researchers at Vital Research in California and tested in facilities under the auspices of a small business grant from the National Institutes of Health (Institute of Medicine 2001). A satisfaction survey was also developed in late 1990s that was similar to REAL. The researchers found reasonable confidence and reliability in preliminary trials, but as of the IOM report these trials were still too preliminary to evaluate survey results and create standards for comparison across nursing homes. New evidence about this approach has not yet appeared in the literature, but numerous attempts have recently been made to expand quality of life survey methods to the cognitively impaired.

For example, a University of Minnesota study measured 11 domains of quality of life (see Kane 2001b) and got information for 2,000 residents from four sources (resident, staff members, external observers, and family). Psychometric testing of these instruments appears promising (Kane et al. 2003), and the differences among them in the domains of life satisfaction considered are striking (Kane et al. 2004). Such variability in part reflects not only the technical difficulty in measuring these constructs, but also the lack of consensus on what are the policy-relevant components of life quality for which facilities should be held accountable.

The ascendant “culture change” models also have limitations as approaches to ensuing quality. The IOM found that these systems have not been widely implemented, that there is only limited evidence that quality management systems significantly impact quality, and that little is known about how exactly quality is impacted (Institute of Medicine 2001). Moreover, these types of reforms may be limited because federal standards and regulations, while useful, are not conducive to culture change and innovation.

Nevertheless, some researchers point to culture change models as one potential method of improving both quality of care and the working environment in nursing homes. Rosalie Kane for example, argues the importance of moving away from a “one-size fits all” model of nursing home care and highlights groups like the Pioneer Network of Long-Term Care, whose members take a more holistic, individualized approach to nursing home care, by “responding to the spirit as well as the mind and body needs; putting persons before tasks; seeking to enjoy residents and staff as unique individuals; acting on the belief that as staff are treated so will residents be treated; beginning decision making with the resident; and accepting risk taking as a normal part of adult life” (Kane 2001a). Still, as she notes and as is reinforced by the 2001 IOM report, these ideas are very difficult to implement, this movement is still fairly recent, and examples of actual implementations remain rare (IOM 2001).

Another attempt at culture change and continuous quality improvement is the Wellspring demonstration in Wisconsin. A group of previously competitive not-for-profit facilities formed an alliance that worked together toward two goals: offering higher quality patient care and creating better working environments for staff members (Stone et al. 2002). The nursing homes share information and techniques in obtaining higher quality care (in terms of outcome-based quality indicators) in a cost-effective manner, as well as engaging in centralized training sessions and encouraging culture change at the management level (Manard 2002; Stone et al. 2002). Reports from those involved in the project suggest that the key to developing this culture of innovation and removing competition was selling the idea of an empowered staff to top management. An evaluation by Stone et al. depicts the model as a success because staff turnover lessened, performance on federal surveys improved, and the staffs were more proactive. Although clear improvements in clinical MDS outcomes could not be seen in the 15-month evaluation, interviews revealed higher quality of life for residents and improved interactions between staff and residents. Finally, no additional net resources were required, and overall costs were generally lower for the facilities involved in Wellspring (Stone et al. 2002).

4.23 Resource barriers

Looming in the path of almost every assessment of quality improvement initiatives is the barrier of low reimbursement, which is said to stretch management and direct care resources so far that they cannot attend to making changes. But it has been difficult to find a direct relationship between reimbursement levels and quality. There are clear links between reimbursement levels and inputs, like staffing, but there is less evidence that reimbursement is directly linked to quality outcomes (Institute of Medicine 2001; Wiener and Stevenson 1998). It has also been very difficult to agree on a minimum level of funding, below which quality is threatened, which was part of the problem with enforcing the Boren amendment (Wiener and Stevenson 1998). Nonetheless, a 2001 Abt Associates study using data from a representative sample of 10 states including over 5,000 facilities, identified nursing assistant and nursing/other licensed professional staffing levels below which facilities were more likely to have quality problems (Centers for Medicare and Medicaid Studies 2002). The minimum levels were 2.8 hours per resident day for the long-stay quality measures for nursing assistants, and 1.3 hours per resident day for the long-stay quality measures for licensed professional staff. The report found that in 2000 the industry was far short of this standard:

...Over 91% of nursing homes have nurse aide staffing levels that fall below the staffing thresholds identified as minimally necessary to provide the needed care processes for their specific resident population. In addition, over 40% of all nursing homes would need to increase nurse aide staffing by 50 percent or more to reach the minimum threshold associated with their resident population, and over 10 percent would need to increase their nurse aide hours in excess of 100 percent.... (Centers for Medicare and Medicaid Studies 2002).

While it may not be feasible to establish case-mix adjusted minimal staffing levels for nursing homes at this point, these results still underline resource constraints in nursing homes. Since reimbursement rates by Medicaid programs and staffing levels have not notably increased since this report, it seems likely that many nursing facilities in the United States still experience a staffing level below that necessary to achieve the quality standards that CMS and others have adopted.

Staffing shortages in nursing homes, particularly for nursing assistants and other paraprofessionals, have complex roots that extend beyond the influence of public sector reimbursement rates: low wages and benefits, lack of career ladders, inadequate training/pre-career programming, difficult working conditions, and unsatisfactory management/ supervision have all been noted as other causes (Bowers and Becker 1992; Close et al. 1994; Eaton 2000; Institute of Medicine 1996b; Institute of Medicine 2001; Mercer, Heacock and Beck 1993; Singh 2004; Stone 2004). This line of research indicates that achieving adequate staffing levels to improve outcomes may require more than higher reimbursement. Such change may require re-designing the jobs of direct care workers and their managers. The barrier created by low reimbursement and resulting limitations on resources is that they block the changes in management, systems, staffing, and practice that promise to foster improvements in quality, particularly along the lines of improvements in patient autonomy and quality of life. Over and over, tests of practice protocols show improvements in quality, but just as surely they are not absorbed into the long-term practices of the test homes (Institute of Medicine 2001). Thus, the low reimbursement levels also frustrate another quality improvement initiative cited by the IOM: environmental change.

OBQI studies have repeatedly pointed to the need for additional staffing and other resources in order to sustain quality process enhancements. In general, methods that improve resident independence (like toilet training or walking improvement programs) or reduce negative outcomes (turning schedule to reduce pressure ulcers, medications monitoring) take more time from staff and may fall to the wayside in a resource-constrained environment (Institute of Medicine 2001). For example, when Schnelle and colleagues implemented successful quality improvement programs for specific care processes (incontinence and restraint use), nursing homes were willing to participate, but they halted programs after oversight and feedback ended because of resource constraints (Schnelle 1997; Schnelle et al. 1992). While current efforts by the QIOs, backed by improved survey processes and CMS publication of deficiencies, may increase the external pressures on nursing home to sustain new practices to a greater extent than at the time of the Schnelle team's work, these programs do not address the resource constraints. Facilities are forced to make business choices between achieving better QI reports or investing in staffing levels and other resources to sustain quality improvements.

At the same time, the IOM committee concludes that quality of life as a featured outcome will continue to be fairly low priority in nursing homes until homes are sufficiently staffed to allow for more individualized focus. Similarly, Schnelle argues that developing standards of care that nursing homes cannot meet puts unfair pressures on administrators and encourages them to comply on paper only. Moreover, survey/evaluation teams focus on medical documentation rather than on clinical outcomes and this encourages only paper compliance. Programs that attempt to deal with substantive changes to care processes require more time: if regulators focus on charts, adoption and innovation are discouraged (Schnelle 1997).

A conceptual and empirical impasse is apparent. The scientific literature has not shown clearly that more resources improve quality, but inadequate resources are associated with worse outcomes and less capacity to adopt better care processes. Yet increases in nursing home expenditures through higher reimbursement rates appear inconsistent with policy initiatives to constrain LTC costs as the population ages and the baby boomer generation starts to need these services. While most nursing homes have found ways to meet basic regulatory standards despite low reimbursement, it is unclear that the desired movement towards a culture of continuous quality improvement and individualized care can be achieved through regulation alone. Since many have concluded that these more fundamental changes in LTC will require more funding, nothing is done, since there is no new funding. Thus, thoughtful experts conclude that regulation will continue to be the primary solution (Institute of Medicine 2001; Wiener 2003).

4.24 Lack of strong impetus for change

A fourth barrier is the lack of a strong impetus for change. As reviewed in the previous section, the pull of the professional and/or research culture is not powerful enough to spur homes to implement protocols. And on the negative side, the state systems for identifying and sanctioning poor performance appear to be underfunded and

lacking in sufficiently powerful tools to coerce facilities to change. GAO found that many states are not enforcing sanctions appropriately, nor is the survey process the same across states (U.S. General Accounting Office 2003b). The IOM advocates immediate sanctions for the highest-level deficiencies, as well as the development of a standardized formulation for choosing appropriate sanctions (Institute of Medicine 2001). CMS is currently promoting reforms of the survey process to improve the reliability of results: for example, targeting chronically poor-performing facilities, chains, and owners; focusing on resident problems; improving sampling procedures and sample sizes; reducing the predictability of the survey process; strengthening consistency of survey determinations; and more strictly and uniformly assessing sanctions for deficiencies (Institute of Medicine 2001). Nonetheless, for the foreseeable future, few of the current LTC actors appear likely to spearhead further changes, and thus the impetus for change will need to come from other sources.

There is a strong impetus for change from the movement of consumers and advocates for strengthening choice and autonomy, but it has been hard for this effort to gain a foothold in nursing homes. Advocates have also had little success in propelling government programs that promote quality of life and quality of care initiatives: While states have been investing in OBQI related activities, it appears that none have created major new regulatory and enforcement initiatives, and none have sought to link sanctions to quality of life shortcomings. In many cases, organized advocacy on the part of the nursing home industry has been a key factor in these legislative patterns.

The movement from within - culture change initiatives - finds itself swimming against the tide of regulation, limited resources, and established practices. Eaton, for example, argues that the market and regulatory system do not really require the low-quality homes to behave differently, since public funds require only a bare minimum of care, and beds remain full in these homes. High-quality homes distinguish themselves by offering better care to consumers, but they are not organized fundamentally differently (Eaton 2000). The IOM observes that federal standards and regulations, while useful, are not conducive to culture change and innovation (for example one group had to get 50 waivers of regulations to implement a demonstration unit (Wolfe 1999). Moreover, the committee notes that these models have not been empirically evaluated yet, including focus on impacts on quality of life/ quality of care, costs, and variations in results due to case mixes.

It is difficult not to avoid the conclusion that the lack of success in finding the political will to promulgate “culture change” in nursing homes reflects a devaluing of elders with disabilities. Low reimbursement and the regulatory orientation to ensuring nursing home quality may send an implicit message about the social value of those who are being cared for through these systems, i.e., Medicaid beneficiaries. There is a clear social stigma attached to receiving Medicaid. We require that the elderly and others with disabilities to both impoverish themselves and face humiliating applications processes to obtain it. Then Medicaid pays so poorly that aides are admittedly overworked, undervalued, and under-supervised; and about a third of them need to go on welfare or food stamps themselves (Health Resources and Services Administration 2004). Since Medicaid beneficiaries are the majority of nursing home residents in most states, the “low value” message spills over to all residents of homes that accept Medicaid. Does the pervasive fatalism in the literature that not much can be done about the quality problems reflect the unwillingness of society to value frail elders more than is minimally necessary? If so, this is not a good mix for ensuring high quality care.

4.3 Barriers to improving quality in community care

At least three additional sets of factors appear as barriers to improving the quality of community care, including the lack of a national policy commitment to community care, the slow emergence of alternative models for financing and delivery of community care, and competing conceptions of quality in these services. Each is described below.

4.3.1 Lack of national commitment to community care

Perhaps the clearest indicator of our societal devaluing of poor, old people with disabilities is found in the absence of a national commitment to community care. The only national community care program is the small Older Americans Act block grant that supports a thin shell of services and care coordination, and this program is implemented in remarkably diverse ways nationwide.

Community care services are not even included in the core service package that states must offer under Medicaid. Rather, Medicaid community care services are either optional (personal care, care management, adult day care) or offered through cumbersome waivers that allow discrimination by age, geography, and type of disability. States vary tremendously in how much they take advantage of optional programs and waivers, how much they supplement OAA and Medicaid with state funds, and how well they coordinate access to services (Leutz et al. 1992; U.S. General Accounting Office 2002a). The widespread use of the Medicare skilled home health benefit to augment weak state efforts to help the oldest and most vulnerable community residents with long-term support, was severely cut in the 1997 Balanced Budget Act (McCall et al. 2003). The extent of access problems has direct effects on whether or not the most basic community care needs of frail elderly are met, which is a first-order measure of quality. According to the IOM:

Access to home and community-based services and especially personal care services for people with disabilities is not uniformly available across states and appears to be largely unmet. The committee believes that access to, and choice of appropriate services, is essential to the quality of care and quality of life for individuals with disabilities. It concluded that research is needed towards developing an appropriate array of community-based LTC services to meet the needs of consumers and assess the quality of the services and outcomes (Institute of Medicine 2001).

More specifically, the current structure of Medicaid fosters vast differences among state community care programs. Among states that had 1915(b) waivers in 1990, spending per aged SSI eligible averaged \$42 per month but ranged from \$1 to \$165. The proportion of all elders not in nursing homes who were served averaged 0.6% across states but ranged from 0.2% or less in the lowest 7 states to between 1.7% and 2.0% in the highest four (Leutz, Sadowsky and Pendleton 1992). When all sources of community care funding were combined (Medicaid waiver, Medicaid personal care, state, and OAA), the inequity persisted: In 1990, only four states spent \$10 or more per elder per month on community care services; 22 spent between \$5 and \$9; and 25 spent between \$1 and \$4 (Leutz 1999b). The situation has not improved a great deal: In 1998 and 1999 among the states that covered personal care either through the optional program (26 states) or waivers (45), the number of Medicaid personal care participants ranged from 7.33/1,000 state residents in the most expansive state to 0.04/1,000 in the lowest. Per capita expenditures ranged from \$91.21 to \$0.02 (LeBlanc, Tonner and Harrington 2001). Similar differences prevail in waiver access and spending: In 1997-8, waiver participants averaged 2.1/1,000 state residents and ranged from 7.91 to 0.62, and per capita waiver expenditures averaged \$29.40 and ranged from \$3.94 to \$96.22 (LeBlanc, Tonner and Harrington 2000).

Evidence for the IOM's point under Medicare is also abundant. For example, even among active patients of skilled home health agency clients in 1993 (while Medicare was in its expansive stage), 45 percent were found to have unmet ADL/IADL needs, and 80 percent of these had three areas of unmet need (Thomas and Payne 1998). Similarly, among those age 70 and over in the 1994 Longitudinal Study of Aging (LSOA), 20 percent of those with ADL need were receiving inadequate care. The likelihood of having unmet needs was associated with lower household income, multiple ADL need, and living alone. Half of those with unmet need reported experiencing a negative consequence, for example, being unable to get to the bathroom when desired (Desai, Lentzner and Weeks 2001). Given that many of the elders who most need community care services have no realistic way of accessing these services in large parts of the country, any national standard for community care quality would be widely violated at its most fundamental level.

4.32 Alternative community care system models

In those states that have committed to serving the poorest and most disabled elders through combinations of Medicaid optional and waiver programs, OAA, state, and other funding, there are alternative, distinct visions of what constitutes a high-quality system. The traditional and prevailing model is to use care managers to assess eligibility and arrange access to a range of covered services, e.g., personal care, homemaker, adult day services, medical transportation, adaptive equipment and devices, and home modifications. In higher quality states, services are provided by agencies that have met the requirements of state contracts (Leutz et al. 1992; Miller, Ramsland and Harrington 1999; U.S. General Accounting Office 2003a).

Service quality is thus influenced by a combination of the appropriateness of eligibility criteria, the adequacy of the package of benefits, the resource limits on benefits (monthly or annual caps are common), how each service is provided, and the care management itself. It is difficult to evaluate quality of any one component without reference to the others.

Competing with this care management/agency model is the Independent Living Model (ILM), whose central tenet is that service users know what is best for themselves and should therefore have the power to control their own care (Batavia, DeJong and McKnew 1991). The ILM model sees the traditional care manager as an unnecessary and intrusive expense, and it holds that agency-based workers don't work closely enough for the person with disabilities. Autonomy and satisfaction are thought to be maximized when the person with disabilities can find, hire, train, and supervise his/her own attendant. A number of states offer this model through Medicaid and state funds. Although advocates of the model point to high rates of satisfaction, particularly with family members employed as aides (Benjamin, Matthias and Franke 2000), states do little to monitor quality directly, and user-hired caregivers are more likely to have low wages and benefits (Tilly and Wiener 2001).

Something of a test of these two models is taking place in several states in Medicaid's Cash and Counseling Demonstration, which gives eligible elders with disabilities the choice of traditional care managed/agency services or cash to employ a worker under the ILM model. Counseling and other supports are offered to help beneficiaries manage. While initial results show high levels of satisfaction among those choosing cash, just as important are the findings that most of those who were offered the choice did not want to be in the demonstration at all, and even among those who participated, nearly as many were not interested in cash (38 percent) as were interested (42 percent), and the rest were unsure (Mahoney et al. 2002). In a more nuanced study of preferences, Sciegaj and colleagues found that a majority of elders, if given the choice, would prefer a defined benefit for LTC based on their level of need, complemented by a professional case management and care delivery system. They also noted complex interactions between race/ethnicity and other factors in determining these preferences (Sceigaj, Capitman and Kaye forthcoming).

These studies offer a view into the potential for a synthesis of the two competing community care concepts: a choice for eligible beneficiaries between self-management and professional advisor care management. While this approach would also balance competing views of quality (choice/autonomy versus professional standards), the community care infrastructures of even the most advanced states are far from being able to offer such a system. Barriers to widespread adoption include developing regulations and supports for the cash and counseling option; systems to aid self-managers in crisis situations or when needed care requires specific skills; programs to help beneficiaries choose and train their providers; work and wage standards to protect care workers; and, of course, approaches to monitoring and comparing quality in the two systems (Leutz 1998; Leutz, Abrahams and Capitman 1993).

Few states are this far along in their thinking, and in the meantime will move forward with varied mix of professionally managed and self-managed services. Having each state responsible for developing its own system and in turn its own approach to quality assurance simplifies the challenge of developing QA systems, since QA is developed with the state system in mind; but fragments the resources that can be devoted to developing a more widely accepted national model for community care QA. This suggests that such a model for process quality would look at "broad varieties across states and communities in practice and resource utilization patterns that are not predicted by community differences in patterns of clinical needs or client preferences" (Capitman, Abrahams and Ritter 1997).

Finally, standing somewhat along side this debate between professionally managed and self-managed services in community care is the Program for All-Inclusive Care for the Elderly (PACE) (Mui 2001). The PACE model, which became a permanent Medicare provider model in the 1997 Balanced Budget Act, pools capitated payments from both Medicare and Medicaid to provide a full package of acute and LTC benefits for frail individuals who are eligible for both programs. PACE uses adult day services settings to bring together a team of providers, which creates a powerful care coordination model, which reduced both hospital and nursing home care and improved participant outcomes compared to a non-randomized control group (Chatterji, Burstein and al. 1998).

Work on instruments to assess and compare quality in PACE are underway, but so far it has been difficult to show clear quality differences from standard community care (Atherly, Kane and Smith 2004; Pacala et al. 2000). The number of PACE sites has been growing since the model achieved program status, and PACE is becoming an important community care strategy in many states. However, the overall impact of the PACE is limited by several of its requirements, including the small size of day centers, the requirement to change physicians to join, the high turnover (mostly due to death) of participants and the focus on dual eligibles. In summary, while PACE is a valuable piece of the community care infrastructure, it cannot be the core – or the quality assurance focus – of a system to serve the broader population of elders.

4.33 Competing concepts of quality

Of course, underlying the alternative community care systems models are competing quality paradigms: on the one hand a regulatory model that relies on structure and process features, and on the other a consumer-directed model intended to foster choice, autonomy, and satisfaction. As we have seen in the historical review, the former grew up largely around community care services for elders, while working-age adults with physical disabilities championed the latter. The competing views have been a barrier to progress in evaluating and ensuring quality, since the two camps have often talked past one another. In more recent years, particularly since coalitions were formed in the early 1990s to back the Clinton LTC plan, there has been some movement to try to find common ground. However, there are still struggles to control thinking and resources.

The staying power of diverse visions of quality is testimony to multiple goals addressed in community care, the wide range of community care services, the varied and complex needs they address, the diversity of home environments and family supports, and the range of preferences and capabilities of service users. Proponents of consumer direction have a relatively simple solution. They point to the intimate and everyday nature of most of the tasks and the ability of service users to find and manage caregivers without the intermediary case manager. Given this, the major criteria for evaluation should be user-centered, e.g., satisfaction, sense of control, and having choice. Proponents cite findings that those who are given control are more satisfied, have fewer unmet needs, and cost the same or less. But these proponents often downplay the self-management challenges at the more skilled end of care or the question of service users who cannot or prefer not to manage their own care.

Proponents of professional involvement and the need for related structure, process, and outcome indicators of community care point to complex interventions (particularly through skilled home health agencies), the vulnerability of some elders (particularly those with complex medical conditions or cognitive deficits), and the challenges of managing community care services. Each potential community care goal –(e.g., convalescence from acute illness, rehabilitation, terminal care, personal care, care in the home, and respite care) requires different understandings and mechanisms for achieving quality; and the assessment must also take into account the impact of socioeconomic factors such as economic status, race/ethnicity, gender, and rural/urban residence as well as care expectations, sense of independence, and availability of informal support (Capitman, Abrahams and Ritter 1997; Caro, Gottlieb and Safran-Norton 2000; Kane 1999; Kane et al. 1994). Whether or not to coordinate community care with medical care is also an issue that affects both the quality of care and the quality of life (Allen and Mor 1997). Although there are models that emphasize coordination, both the standard care manager/agency model and the ILM model do little to address this issue (Leutz 1999a).

An objective analysis of the ILM and care manager/agency models would likely show that this is a “both-and” rather than an “either-or” situation. Both of these visions are true, but it is difficult for everyone involved to maintain such a broad perspective. Kane and colleagues' interviews of users, consumer representatives, providers, paraprofessionals, payers, and regulators found that they valued different outcomes. Providers, insurers, and regulators felt that outcomes were most important, while consumer groups ranked enabling indicators most important. Insurers were concerned most about costs and outcomes—others about interpersonal components of community care, normalization, balancing quality of life with safety, flexible, negotiated care plans, affordability, appropriateness, case management, and accountability. Goals also differed by the type of patient, although some goals were always supported (“freedom from exploitation and abuse, satisfaction with care, physical safety, affordability and maintenance or improvement of physical functioning”) (Kane et al. 1994).

4.4 Barriers in housing plus services models

Barriers to improving quality in housing-plus-services models (board and care, adult group homes, assisted living, adult foster care, continuing care retirement communities) involve the same essential issues as in community care and nursing home care, but the history and context differ. Compared with nursing facilities and even publicly reimbursed community care, there have been more minimal state quality requirements for housing-plus services models (mostly structural items about space, staffing, and services). However, the questions on the table are whether to require more, and if so, what the requirements should be. Very much alive is the question of whether quality in these settings should be assessed through resident-focused satisfaction and autonomy measures or a combination of structure, process, and assessment-based outcome measures.

4.41 Variation in regulations and models

The wide variation across states and settings in terms of terminology, price, amenities, service levels, regulation/licensure, and size makes it impossible to generalize about the quality of care in housing-plus-services settings or approaches to improving quality. Ironically, due to the lack of regulation and the range of approaches, housing plus services can be what the consumer chooses to see: anything ranging from a great opportunity for innovation and choice to an easy target for those concerned with fraud and rip-offs (Kane 2001b). Recognizing these potentials, 28 states as of 2003 had developed regulations for assisted living as a discrete service category that emphasized concepts such as independence, dignity, privacy, and autonomy as well as basic structural and process requirements. Who should be responsible for deciding and monitoring? States who impose a regulatory approach as more disabled residents are cared for in these settings (Aud and Rantz 2004), trade associations setting standards for and certifying their own members, or consumers shopping around in the market?

4.42 Variation in resources

Another barrier to quality in these settings is the wide variation in prices, and therefore in resources available for care and amenities. A study of 94 board and care homes - some regulated, some not - (Lyon 1997) found that higher payment was a better predictor of high quality than whether or not homes were regulated. In many states there is a single regulatory category that covers everything from residences for elders receiving SSI plus housing supplements to residences serving the high-end private pay market. Yet higher payment for assisted living programs may not ensure more appropriate care. In a 1999 study of 20 nursing homes, Yee et al. found that higher priced facilities were serving notably more medically complex and disabled persons, yet these facilities were also associated with higher rates of avoidable care problems and negative health outcomes (Yee et al. 1999).

4.43 Lack of research

In recent years, the fastest growing segment of these models has been private assisted living. Regrettably, the relative newness and the private nature of assisted living have limited the development of a body of scientific work on these programs. Because of the many different rules and requirements for these facilities from state to state, most references to assisted living note how difficult it is to learn what is going on in assisted living facilities and how programs might be improved to better meet quality of care goals (Institute of Medicine 2001). Nonetheless, a few studies have focused on the factors associated with continued tenure in assisted living or discharge to higher levels of care.

For example, (Ball et al. 2004) explore the factors associated with decline in functioning and discharge to higher levels of care for assisted living residents, finding that the fit between the services of the facility and the individual's health status was the strongest predictor of negative outcomes. Similarly, Aud (2004) in a qualitative study of 14 Missouri facilities found that discharge to higher levels of care was associated with cognitive and physical functioning declines (Aud 2004).

Aud also notes that facilities have few formalized mechanisms for tracking such declines and thus it is most often the emergence of aggression, wandering, and other behaviors that run counter to facility expectations that signals functional losses and need for intensive care.

4.5 Barriers to the market model for furthering quality

An overlay to some of the thinking about quality improvement is a hope that the market – (informed consumers choosing from competing providers) is the best way for people to find the type of care that best suits them, and also to sort out the good from the bad among the providers. For example, the IOM report ranks consumer information and market competition as one of three approaches to quality. The effort to publish OBQI data on nursing homes and home health agencies is but one expression of this perspective. However, these expectations of market approach are not yet supported by empirical evidence. We could not locate studies that examined how LTC seekers use these data, and such data are not available for assisted living or similar programming geared to elders who live in the community but are ineligible for Medicaid. Little information is currently available about the ability of market forces to ensure quality in housing-plus-services or other LTC settings, and the evidence from the medical care sector underscores how difficult it is to improve consumer understanding of health care choices. For example, Hibbard and colleagues gave Medicare beneficiaries and an under age 65 sample information of various sorts about health care choices and found that elders made many more errors, and that erroneous interpretations were highest for those in poorer health, with less education, and those who were older. Overall, they estimated that 56 percent of the Medicare population would perform at the high-error end of their comprehension index (Hibbard et al. 2001). Similarly, only 11 percent of beneficiaries in a high-penetration HMO market were judged to have adequate knowledge of HMOs to make an informed decision (Hibbard et al. 1998). In the absence of empirical supports for the market model, a perspective that emphasizes professional and provider responsibility and collaboration between regulators and providers remains compelling.

Moreover, although the LTC marketplace is full of products, consumers face barriers to adoption if they are unable to afford those products. Compared to the highly regulated nursing facility, the amenities and care in other modalities vary directly and substantially with price, e.g., in board and care or comparable models (Lyon 1997). Thus, the market poses substantial quality threats to low-income elders, while there options for wealthier which appear more attractive. Sorting out what appears attractive from what is quality care is another matter. Both finding the right option in the marketplace, and ensuring that high quality help is obtained require well-informed consumers. Informing consumers requires overcoming barriers in understanding of both the range of LTC options, the particular features best suited to the individual, and the characteristics particular facilities. Understanding the range of options is made more complex by the broad array of service alternatives, each of which may be called by various names, and overlap in what services they offer. There are residential options, community-based options, in-home care options, and devices. There are financing and management – options—both public and private, with complex criteria for deciding which ones apply to you. Government and providers have developed a wide array of materials to teach the public about the market, and although a daunting task,, an intelligent consumer can make informed choices among types and settings of care.

Understanding the details of each service option is another matter. After choosing an approach, how can a consumer sort among LTC providers, suppliers, care managers, and insurers on the basis of quality? This is a more difficult barrier because provider associations and the government are reluctant to compare the quality of individual providers. In some cases (e.g., hospital discharge planners), providers are prohibited from sharing what they know. The solution most states have adopted is to set standards for categories of providers, and then consumers are told about the standards and advised whether providers meet them. This is a start, but standards in many areas of LTC are minimal, and enforcement efforts are also weak, which ensures that difficult-to-detect quality differences will remain.

The Nursing Home Compare web site run by CMS takes a big step to distinguish the differences among facilities, but also reveals the pitfalls of doing so. The lack of good risk adjustment makes it easy for consumers to misinterpret the site's quality indicators (Centers for Medicare and Medicaid Services 2001). Angelelli found that homes that closed were higher on violations than those that didn't, suggesting that violation information could speed this trend (Angelelli et al. 2003). The next level of hope for information in the market is for consumers to make their own judgments about private market options like assisted living. There are reasons to question how well consumers can distinguish quality. The recent IOM study concluded that consumers are not currently given enough information when choosing assisted living facilities. Interviews of assisted living residents found that family members had usually chosen the facility for them without their involvement (Yee et al. 1999).

5. Conclusions and Recommendations

Understanding quality in terms of the goals of public policy with respect to LTC fits within the post-modernist understanding that, rather than being timeless and absolute, quality is a contested and ever-changing concept. The debates over its definition, measurement, and assurance occur within the context of broader public policy debates about health care and an aging population. Thus the definition of quality in LTC has remained intimately linked to public policy goals.

As the nation saw rapid growth in the impoverished LTC population in the 1950s and 1960s and sought to help states and localities shoulder this new burden, the most pressing issues were building capacity and ensuring safety in the physical plant. Although the LTC population continued to grow in the early years after Medicare was approved, need for professional chronic care services remained relatively unusual and fraught with the potential for disgrace and despair. As the nation sought a comprehensive approach to meeting complex health needs of elders, and the capacity and basic safety of LTC facilities began to meet expectations, attention turned to quality of care, which came to be defined as avoiding adverse events and outcomes. The 1970s and 1980s also saw the emergence of professional home and community care as concerns with LTC costs and the political force of disabled adults, elders and advocates in calling for choices among alternative services grew more distinct.

As more professionals and researchers turned to focus on LTC problems, quality was viewed in terms of practices consistent with expert consensus about how to achieve specified goals. The increasing professionalization of LTC was seen as a potential antidote to the gloomy public view of facilities and increasing appreciation for the relatively high lifetime incidence of chronic care needs. The focus on health-related goal attainment in LTC also highlights other, increasingly influential healthcare policy goals for these services, such as avoiding costs associated with acute exacerbations of chronic conditions and premature declines in functioning. These efforts reflected the concerns in the post-hospital prospective payment era in fitting LTC with acute care. Long-term care also came to be promoted as a mechanism to increase the cost-effectiveness of health care for people with chronic disabling conditions by substituting lower levels of care (in terms of intensity, technological sophistication, and staffing requirements) for more expensive acute care ones.

A new view of LTC policy goals seems to be emerging and with it come new avenues in the quest for quality. As the likelihood of needing LTC has steadily increased, so has the period of time that individuals survive with LTC needs. Fewer elders have extended informal networks to rely upon and the life patterns of younger generations do not lend to caregiving roles as well as in the past. Most of us now expect to receive formal LTC services at some point in our lives. This has led to broader generational shifts in quality of life expectations among elders and their loved ones. Another force for redefinition of quality in LTC has been new recognition among professionals of the potential to not only avoid the worst outcomes but to actually improve the well-being of elders and others with the most severe disabling conditions. In this context, LTC quality concepts are expanding to include quality of life, dignity, access to alternative services, autonomy, subjective well-being, and satisfaction with care.

While some advocates have indicated that these dimensions of quality should form the primary target of regulatory and other improvement initiatives, others have emphasized the increasing intensity of medical needs and technological sophistication of services in these settings. Health care costs continue to spiral, and LTC settings can contribute to constraining the rate of this growth. From this perspective, the OBQI framework, with its focus on avoiding negative outcomes by improving care process, needs to be implemented more fully.

An integration of these perspectives may be emerging that defines policy goals for LTC as both supporting overall health system effectiveness by maximizing functioning and well-being for elders and others with disabilities, and supporting the dignity of individuals with LTC needs and their informal caregivers by easing the financial and psychosocial barriers to self-determined quality of life and community participation. Quality in LTC, from this integrated perspective, requires that services help elders to attain the best possible health and functional status they can, while enjoying as meaningful and “normal” a life as is feasible. In this context, LTC has come to be viewed as both a challenge to health services financing and delivery, and as the defining feature of a significant phase in normal aging. This ascendant view—the normalizing of chronic care needs and LTC service responses—creates a particular challenge for those accountable for the quality of LTC. Public and private sector financing and organization of care delivery policies and practices are still framed primarily from a rare-event medical perspective. This perspective yields programming that is poorly matched with our shared striving for pleasing settings and meaningful activities during the long last acts of modern lives.

While this integration of quality of life and quality of care concepts as the basis for LTC regulatory and industry efforts to improve quality may be gaining in popularity, the LTC sector appears caught on the wrong side of a deepening cultural chasm. Policy goals that include constraining the growth of medical care expenditures have contributed to limited growth in reimbursement for these services and the absence of a national policy framework to enhance access to community services. Faced with worsening resource constraints, a regulatory quality assurance approach that lacks sufficiently powerful incentives for adherence, and a collaborative quality improvement strategy that pays insufficient attention to fostering broader organizational change, a culture of compliance with minimal standards has emerged.

LTC providers are inconsistent in their embrace of existing medically oriented process enhancements and simply lack the time, money and other resources to address quality of life enhancements on a systematic basis. This tendency is reinforced by available measures and indicators of quality that only suggest problems in care process and outcomes but do not offer benchmarks for excellence. This stalemate underscores the need for a new national dialogue on our values and policy goals with respect to LTC.

Beyond this policy and program stalemate, there are continuing important gaps in our knowledge about the OBQI strategy, including, issues about measurement and issues about the change process:

- Controlling for case-mix in QI measurement
- Linking staffing, job designs, and performance
- Measures for quality of life/care satisfaction
- Linking quality of life/satisfaction with QIs
- Organizational factors associated with adoption of improved care processes
- Roles of federal and state sanctions in performance improvement
- Community care QI measures that account for preferences, informal caregivers, and inadequate care access
- Extension of QI measures to care continuity and coordination issues
- Addressing cultural and individual preferences in QI measures

Recognizing the need both for policy re-orientation and continuing technical development of quality measurement and assurance approaches, we offer the following recommendations for consideration by the National Quality Forum:

I. Encourage a national policy discussion on LTC goals

- A. **Access to community care and unmet needs:** Not since the period between the Pepper Commission (Commission 1990) and the subsequent failure of the Clinton healthcare reform initiative has there been a sustained national debate on the accessibility of community care services (Wiener et al. 2001). Rather than a national policy that ensures access to quality community care for elders based on need, we have a poorly funded patchwork quilt of programs that leave many elders unserved and underserved. Difficulty in accessing needed care and the surprisingly high prevalence of unmet needs for assistance in daily living and disease management activities among elders recently discharged from services covered by Medicare and other insurance loom as quality challenges for community care. Difficulties in building and sustaining a community care workforce—a crucial element in LTC quality—have also been linked to the absence of a national framework for community care. Other industrialized countries, such as Germany and Japan, have concluded that social insurance for all LTC is needed. Whether or not such a universal approach will be selected in the US is unclear, in part because we have not created the circumstances for full-scale public exploration of this issue. LTC and other health providers and advocates need to lead an effort to increase public awareness of the extent of unmet needs among disabled elders, the importance of these needs, and the range of policy options for addressing these problems.
- B. **Quality of life and quality of care in nursing homes and other housing-plus-services settings.** Many of the current critiques of nursing home quality assurance initiatives focus on their predominant attention to medically oriented components of care quality, while lacking sufficient attention to the quality of life for residents. By contrast, private sector assisted living has emerged as a largely unregulated market that offers elders many of the services of nursing homes in more pleasant settings that support resident autonomy. Yet these providers are not being held accountable for offering care consistent with emerging process and outcome standards. One solution would be to extend the OBQI approach to housing-plus-service settings, irrespective of payment sources, while investing the needed public resources and attention to creating more normal and engaged lives for nursing home residents. Yet some critics of nursing home care and advocates for assisted living view these divergent patterns as positive impacts of a free market: individuals are given the choice among very different types of services. Yet how much choice is really available? Do assisted living residents actually prefer greater safety risks and less attention to management of their health conditions? Do nursing home residents really prefer sacrificing aspects of the “the good life” for better attention to their health needs? It seems that the National Commission for Quality Long-term Care and others could foster a real national debate on these issues that seeks to articulate a clearer basis for quality long-term care. One outcome of such a debate might be the articulation of a “bill of rights” for disabled adults that emphasizes more accurate disclosure by assisted living facilities with respect to process and outcome measures of care quality in relationship to nursing facility quality of care indicators, while ensuring that nursing facility regulation and quality improvement target creation of more normal and engaged lives for residents. Alternatively, such a national dialogue might conclude that public investment and regulation should continue to primarily target avoidance of unwarranted negative outcomes while acknowledging that we as a nation are not committed to ensuring that elders who can not afford private services can also experience a meaningful and “normal” quality of life. Whatever the outcome, continued progress in LTC quality assurance appears to require development of a new consensus on the best resolution to the current quality of life/quality of care divide.

2. National Demonstration of Nursing Home Culture Change Models:

Surely one of the primary impediments to conducting a national dialogue on quality of life and quality of care in nursing homes is our uncertainty about the feasibility, costs, and outcomes that might be achieved through re-orienting nursing homes towards a culture that emphasize quality of life for residents, quality of work life for staff, and continuous improvement in quality of care.

The Wellspring demonstrations in Wisconsin and similar proposals provide tantalizing glimpses of how nursing home culture, operations, and outcomes may be re-oriented and seem to imply that some improvements in resident and staff satisfaction can be obtained without increasing costs or sacrificing avoidance of negative outcomes. It is unclear whether or not these ideas can be replicated across diverse facilities or whether or not variants of this approach can achieve social environment changes and improved outcomes across a range of care quality measures. The National Commission for Quality Long-term Care and others could promote implementation and comprehensive evaluation of alternative culture change models for nursing homes. Results from this kind of initiative could provide some of the information needed to inform policy in this area.

3. Continued Attention to OBQI:

There is no denying the positive achievements associated with the current national framework for outcome-based quality improvement that includes well-tested measures of care process and outcome variation, dissemination of quality findings, and resources to support collaborative efforts to improve quality. Yet many analysts point with disappointment to the continued presence of quality deficiencies and remain concerned with the pace of adoption of state-of-the-art care processes. Several initiatives might be considered in this area.

- A. Holding states accountable for quality monitoring and enforcement: Although states are given responsibility by Federal law for monitoring the quality of care in nursing homes and other LTC settings, they are not being held accountable for the assertiveness of these efforts or achievement of overall quality improvements. Evidence suggests that while some states have been tightly focused on these roles and cooperating with other quality improvement initiatives, others have not. It is unclear to what extent this reflects state funding levels for quality assurance, need for technical assistance to states, or lack of adequately powerful mechanisms for enforcement. The separation of the QIO-led nursing home and home health quality initiatives from the monitoring and enforcement roles of states may also be an element. New initiatives might explore either increasing the resources available to states for monitoring, enforcement, and collaborative improvement efforts, or transferring more of the monitoring and enforcement capacity to the QIOs.
- B. Organizational demonstration and research initiatives on accelerating adoption of quality process: Even with new information on performance relative to national quality of care indicators and availability of support from the QIOs, there has been uneven adoption by nursing homes of state-of-the-art care processes. Lack of adoption of these new protocols and technologies may simply reflect their relative novelty. Yet experience in other contexts suggests that diffusion of innovation can be accelerated with greater attention to the interplay between the innovation itself, the adopting organization, and external forces. As the alignment between the interests and understandings of stakeholders increases, and as the added value associated with innovation is better communicated, diffusion can occur more rapidly. New research initiatives are needed to understand how and why some nursing homes but not others are adopting new care protocols. Demonstrations of organizational change models that have been associated with adoption of innovations in other settings could be directed to nursing homes.
- C. Extension of current OBQI to Assisted Living: As noted above, the assisted living market is inconsistently regulated across the nation yet it is serving populations that at least partially overlap with nursing home residents in service needs and outcome trajectories. From a technical perspective, the OBQI framework could be readily extended to these settings. Such an extension, however, might require Federal legislation that established national definitions and quality standards for assisted living. In the absence of federal action, individual states could be encouraged to enact their own standards for assisted living that include collection and reporting of MDS data and survey processes that parallel those for nursing homes.

- D. Exploring linkages among QI measures and care improvement initiatives: The current collaborative quality improvement efforts target single QI measures and associated processes. How these efforts affect other care process within the same facilities is unknown. There is no available data on whether improvement in wound care, for example, generalizes to improved attention to pain. One of the primary strategies for accelerating improvement in care process may be to target for quality improvement efforts those processes that influence multiple outcomes. It is also possible that no such sentinel processes can be found. New research and demonstration efforts are needed to understand the linkages between QI measures and the process changes that can influence multiple outcomes.
- E. OBQI measures for community settings: We have described several of the factors that may limit the extension of the OBQI framework to community care, including: striking problems with accessibility of formal community care, absence of choice of providers and services in many communities, inadequate homecare workforce, intersection of formal and informal provision in these settings, and the central importance of patient autonomy and care satisfaction among community residents with LTC needs. Because of these factors, it is unclear what indicators of inadequate response to specific functional limitations or medical management requirements in these settings would tell us. There is no national policy framework that could even support requirements for collection and reporting, let alone sanctioning of inadequate care. Nonetheless, it may be possible to articulate some preliminary minimal standards for community care quality that focus on the kinds of glaring examples of unmet need that have been reported. Prior studies suggest that consensus can be achieved about adequate responses to disability in the community. An instrument that reflects these standards could be broadly promulgated and state eldercare programs could be encouraged to require documentation of care relative to these standards. While this approach cannot be expected to address the full range of unmet needs and poor care in the community, it might at least provide evidence about care for individuals and communities that would support quality LTC advocacy efforts.

References

- AARP. 1996. "A national overview of adult foster care for the elderly." Washington, DC: Public Policy Institute.
- Abt Associates. 2001. "Final Report: Identification and Evaluation of Existing Quality Indicators that are Appropriate for Use in Long-Term Care Settings." Cambridge, MA: Abt Associates.
- Agency for Healthcare Research and Quality. 2003. "National Healthcare Quality Report." Rockville, MD: DHHS.
- AHQA. 2004. "Fact Sheet: Nursing Home Results." American Health Quality Association.
- Allen, B. L., P. Burt, C. Roychoudhury, and B. Chen. 2004. "Analysis of OBQI outcomes in participating Michigan home health agencies." *J Nurs Care Qual.* 19:149-55.
- Allen, S. M., and V. Mor. 1997. "The prevalence and consequences of unmet need. Contrasts between older and younger adults with disability." *Med Care.* 35:1132-48.
- Angelelli, J., V. Mor, O. Intrator, Z. Feng, and J. Zinn. 2003. "Oversight of nursing homes: pruning the tree or just spotting bad apples?" *Gerontologist.* 43 Spec No 2:67-75.
- Atherly, A., R. L. Kane, and M. A. Smith. 2004. "Older adults' satisfaction with integrated capitated health and long-term care." *Gerontologist.* 44:348-57.
- Aud, M. A. 2004. "Residents with dementia in assisted living facilities. The role of behavior in discharge decisions." *J Gerontol Nurs.* 30:16-26.
- Aud, M. A., and M. J. Rantz. 2004. "Quality concerns in assisted living facilities." *J Nurs Care Qual.* 19:8-9.
- Baier, R. R., D. R. Gifford, C. H. Lyder, M. W. Schall, D. L. Funston-Dillon, J. M. Lewis, and D. L. Ordin. 2003. "Quality improvement for pressure ulcer care in the nursing home setting: the Northeast Pressure Ulcer Project." *J Am Med Dir Assoc.* 4:291-301.
- Ball, M. M., M. M. Perkins, F. J. Whittington, B. R. Connell, C. Hollingsworth, S. V. King, C. L. Elrod, and B. L. Combs. 2004. "Managing decline in assisted living: the key to aging in place." *J Gerontol B Psychol Sci Soc Sci.* 59:S202-12.
- Batavia, A. I., G. DeJong, and L. B. McKnew. 1991. "Toward a national personal assistance program: the independent living model of long-term care for persons with disabilities." *J Health Polit Policy Law.* 16:523-45.
- Bates-Jensen, B. M., M. Cadogan, D. Osterweil, L. Levy-Storms, J. Jorge, N. Al-Samarrai, V. Grbic, and J. F. Schnelle. 2003. "The minimum data set pressure ulcer indicator: does it reflect differences in care processes related to pressure ulcer prevention and treatment in nursing homes?" *J Am Geriatr Soc.* 51:1203-12.
- Benjamin, A. E., R. Matthias, and T. M. Franke. 2000. "Comparing consumer-directed and agency models for providing supportive services at home." *Health Serv Res.* 35:351-66.
- Berlowitz, D. R., A. S. Ash, G. H. Brandeis, H. K. Brand, J. L. Halpern, and M. A. Moskowitz. 1996. "Rating long-term care facilities on pressure ulcer development: importance of case-mix adjustment." *Ann Intern Med.* 124:557-63.
- Berlowitz, D. R., H. Q. Bezerra, G. H. Brandeis, B. Kader, and J. J. Anderson. 2000. "Are we improving the quality of nursing home care: the case of pressure ulcers." *J Am Geriatr Soc.* 48:59-62.
- Berlowitz, D. R., GJ Young, EC Hickey, D Saliba, BS Mittman, E Czarnowski, B Simon, J. J. Anderson, A. S. Ash, LV Rubenstein, and M. A. Moskowitz. 2003. "Quality Improvement implementation in the nursing home." *Health Serv Res.* 38:65-83.
- Bowers, B., and M. Becker. 1992. "Nurse's aides in nursing homes: the relationship between organization and quality." *Gerontologist.* 32:360-6.
- Boyle, V. L., C. Roychoudhury, R. Beniak, L. Cohn, A. Bayer, and I. Katz. 2004. "Recognition and management of depression in skilled-nursing and long-term care settings: evolving targets for quality improvement." *Am J Geriatr Psychiatry.* 12:288-95.
- Brown, K. S. 2004. "Elderweb: Long-Term Care History." Elderweb. Available online at <http://www.elderweb.com>. Accessed on August 9, 2004.
- Buelow, J. R., and F. A. Fee. 2000. "Perceptions of care and satisfaction in assisted living facilities." *Health Mark Q.* 17:13-24.
- Cadogan, M. P., J. F. Schnelle, N. Yamamoto-Mitani, G. Cabrera, and S. F. Simmons. 2004. "A minimum data set prevalence of pain quality indicator: is it accurate and does it reflect differences in care processes?" *J Gerontol A Biol Sci Med Sci.* 59:281-5.
- Capitman, J. 1989. "Policy and program options in community oriented long-term care." *Annual Review of Geriatrics*, edited by M.P. Lawton. New York: Springer Publishing.
- . 2003. "Effective coordination of medical and supportive services." *J Aging Health.* 15:124-64.
- Capitman, J., R. Abrahams, and G. Ritter. 1997. "Measuring the adequacy of home care for frail elders." *Gerontologist.* 37:303-13.
- Capitman, J., and M. Sciegaj. 1995. "A contextual approach for understanding individual autonomy in managed community long-term care." *Gerontologist.* 35:533-40.
- Caro, F. G., A. S. Gottlieb, and C. Safran-Norton. 2000. "Performance-based home care for the elderly: the quality of circumstance protocol." *Home Health Care Serv Q.* 18:1-48.
- Centers for Medicare and Medicaid Services. 2001. "Medicare Quality Improvement Priorities." Baltimore, MD: USDHHS.
- . 2002. "Report to Congress: Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes; Phase II Report." Baltimore: CMS Prepared by Abt Associates, Inc.
- . 2003. "Medicare Quality Improvement Priorities." Baltimore, MD: USDHHS.
- Centers for Medicare and Medicaid Studies. 2002. "Report to Congress: Appropriateness of Minimum Nurse Staffing Ratios in Nursing Homes; Phase II Report." Baltimore: USDHHS, Prepared by Abt Associates, Inc.
- Chan, L., S. Beaver, R. F. Maclellan, A. Jha, M. Maciejewski, and J. N. Doctor. 2002. "Disability and health care costs in the Medicare population." *Arch Phys Med Rehabil.* 83:1196-201.
- Chatterji, P., N. R. Burstein, et al. 1998. "Evaluation of the PACE Demonstration: The impact of PACE on participant outcomes." Cambridge, MA: Abt Associates.
- Close, L., C.L. Estes, K. Linkins, and E. Binney. 1994. "A Political Economy Perspective on Front-Line Workers in Long-Term Care." *Generations.* 18:23-27.
- Coleman, E. A., J. M. Martau, M. K. Lin, and A. M. Kramer. 2002. "Pressure ulcer prevalence in long-term nursing home residents since the implementation of OBRA '87. Omnibus Budget Reconciliation Act." *J Am Geriatr Soc.* 50:728-32.
- Commission, The Pepper. 1990. "A call for action." U.S. Bipartisan Commission on Comprehensive Health Care.
- Crown, W. H., D. A. Ahlburg, and M. MacAdam. 1995. "The demographic and employment characteristics of home care aides: a comparison with nursing home aides, hospital aides, and other workers." *Gerontologist.* 35:162-70.
- Desai, M. M., H. R. Lentzner, and J. D. Weeks. 2001. "Unmet need for personal assistance with activities of daily living among older adults." *Gerontologist.* 41:82-8.
- Donabedian, A. 1985. "Twenty years of research on the quality of medical care: 1964-1984." *Eval Health Prof.* 8:243-65.
- Eaton, S. C. 2000. "Beyond 'unloving care': linking human resource management and patient care quality in nursing homes." *International Journal of Human Resource Management.* 11:591-616.
- Epps, R.P., M.W. Manley, C.G. Husten, T.P. Houston, L.R. Martin, and T.J. Glynn. 1998. "Transfer of preventive health programs to physicians' practices through medical organizations." *Am J Prev Med.* 14:25-30.
- Feder, J., W. Scanlon, J. Edwards, and J. Hoffman. 1989. "Board and care: Problem or solution?" 27-39 In *Preserving independence, supporting needs: The role of board and care homes*, edited by G. Gaberlavage M. Moon, and S.J. Newman. Washington, D.C: AARP Public Policy Institute.
- Feder, J., H. Komisar, and M. Niefeld. 2000. "Long-term care in the United States: an overview." *Health Affairs.* 19:40-56.
- Feldman, P.H. 1996. *Labor Market Issues in Home-based Care for a New Century*. Malden, MA: Blackwell Publishers.
- GAO. 1989. "Board and care: insufficient assurances that residents' needs are identified and met." General Accounting Office, Washington, D.C.
- Geron, S. M., K. Smith, S. Tennstedt, A. Jette, D. Chassler, and L. Kasten. 2000. "The home care satisfaction measure: a client-centered approach to assessing the satisfaction of frail older adults with home care services." *J Gerontol B Psychol Sci Soc Sci.* 55:S259-70.

References

- Glasgow, R.E., E. Lichtenstein, and A.C. Marcus. 2003. "Why don't we see more translation of health promotion research to practice? Rethinking the efficacy-to-effectiveness transition." *Am J Public Health*. 93:1261-7.
- Hadley, J., D. Rabin, A. Epstein, S. Stein, and C. Rimes. 2000. "Posthospitalization home health care use and changes in functional status in a Medicare population." *Med Care*. 38:494-507.
- Harrington, C., D. Zimmerman, S. L. Karon, J. Robinson, and P. Beutel. 2000. "Nursing home staffing and its relationship to deficiencies." *J Gerontol B Psychol Sci Soc Sci*. 55:5278-87.
- Hawes, C., J. N. Morris, C. D. Phillips, B. E. Fries, K. Murphy, and V. Mor. 1997. "Development of the nursing home Resident Assessment Instrument in the USA." *Age Ageing*. 26 Suppl 2:19-25.
- Hawes, C., C. D. Phillips, M. Rose, S. Holan, and M. Sherman. 2003. "A national survey of assisted living facilities." *Gerontologist*. 43:875-82.
- Hawes, Catherine, Miriam Rose, and Charles D. Phillips. 1999. "A National Study of Assisted Living for the Frail Elderly." Beachwood, Ohio: Menorah Park Center for Senior Living.
- Hays, R. D., A. L. Siu, E. Keeler, G. N. Marshall, R. M. Kaplan, S. Simmons, D. el Mouchi, and J. F. Schnelle. 1996. "Long-term care residents' preferences for health states on the quality of well-being scale." *Med Decis Making*. 16:254-61.
- Health Resources and Services Administration. 2004. "Nursing Aides, home health aides, and related health care occupations--national and local workforce shortages and associated data needs." Washington DC: National Center for Health Workforce Analyses, Bureau of Health Professions.
- Henry, M.E., and J. Capitan. 1995. "Finding Satisfaction in Adult Day Care: An Analysis of a National Demonstration of Dementia Care and Respite Services." *Journal of Applied Gerontology*. 14:302-20.
- Hibbard, J. H., J. J. Jewett, S. Engelmann, and M. Tusler. 1998. "Can Medicare beneficiaries make informed choices?" 181-93 In *Health Aff (Millwood)*.
- Hibbard, J. H., P. Slovic, E. Peters, M. L. Finucane, and M. Tusler. 2001. "Is the informed-choice policy approach appropriate for Medicare beneficiaries?" 199-203 In *Health Aff (Millwood)*.
- Hirdes, J. P., B. E. Fries, J. N. Morris, N. Ikegami, D. Zimmerman, D. M. Dalby, P. Aliaga, S. Hammer, and R. Jones. 2004. "Home Care Quality Indicators (HCQIs) Based on the MDS-HC." *Gerontologist*. 44:665-79.
- Holstein, and Cole. 1996. "The evolution of long-term care in America." *The Future of Long-Term Care*, edited by R. H. Binstock, L.E. Cluff, and O. Venmering. Baltimore: Johns Hopkins University Press.
- Institute of Medicine. 1986. *Improving the Quality of Care in Nursing Homes*. Washington D.C.: Institute of Medicine, National Academy Press.
- . 1996a. *Best at Home: Assuring Quality Long-Term Care in Home and Community-Based Services*. Washington D.C.: IOM, National Academy Press.
- . 1996b. *Nursing Staff in Hospitals and Nursing Homes: Is it Adequate?* Washington D.C.: IOM, National Academy Press.
- . 2001. *Improving the Quality of Long-Term Care*. Washington D.C.: Institute of Medicine, National Academy of Sciences.
- IOM. 2001. "Improving the Quality of Long-Term Care." Washington, DC: Institute of Medicine.
- Jette, A. M., K. W. Smith, and S. M. McDermott. 1996. "Quality of Medicare-reimbursed home health care." *Gerontologist*. 36:492-501.
- Kane, R. A. 1999. "Goals of home care: therapeutic, compensatory, either, or both?" *J Aging Health*. 11:299-321.
- . 2001a. "Long-term care and a good quality of life: bringing them closer together." *Gerontologist*. 41:293-304.
- Kane, R. A., R. L. Kane, L. H. Illston, and N. N. Eustis. 1994. "Perspectives on home care quality." *Health Care Financing Review*. 16:69-90.
- Kane, R. A., K. C. Kling, B. Bershadsky, R. L. Kane, K. Giles, H. B. Degenholtz, J. Liu, and L. J. Cutler. 2003. "Quality of life measures for nursing home residents." *J Gerontol A Biol Sci Med Sci*. 58:240-8.
- Kane, R. L. 2001b. "Scaling the heights of quality of life." *J Clin Epidemiol*. 54:1079-80.
- Kane, R. L., B. Bershadsky, R. A. Kane, H. H. Degenholtz, J. Liu, K. Giles, and K. C. Kling. 2004. "Using resident reports of quality of life to distinguish among nursing homes." *Gerontologist*. 44:624-32.
- Kemper, P., R. Applebaum, and M. Harrigan. 1987. "Community care demonstrations: what have we learned?" *Health Care Financ Rev*. 8:87-100.
- Kurowski, B., and P. Shaughnessy. 1982. "The measurement and assurance of quality." 103-133. In *Long-term Care: Perspectives from research and demonstrations*, edited by R. Vogel and H. Palmer. Washington D. C.: USDHHS Health Care Financing Administration.
- LeBlanc, A. J., M. C. Tonner, and C. Harrington. 2000. "Medicaid 1915(c) home and community-based services waivers across the states." *Health Care Financ Rev*. 22:159-74.
- . 2001. "State Medicaid programs offering personal care services." *Health Care Financ Rev*. 22:155-73.
- Leutz, W.N. 1998. "Home Care Benefits for Persons with Disabilities." *American Rehabilitation*. 24:6-14.
- . 1999a. "Five laws for integrating medical and social services: lessons from the United States and the United Kingdom." *Milbank Q*. 77:77-110, iv-v.
- . 1999b. "Policy choices for Medicaid and Medicare waivers." *Gerontologist*. 39:86-93.
- Leutz, W.N., R. Abrahams, and J. Capitan. 1993. "The administration of eligibility for community long-term care." *Gerontologist*. 33:92-104.
- Leutz, W.N., J. Capitan, M. MacAdam, and R. Abrahams. 1992. *Care for frail elders: developing community solutions*. New York: Auburn House.
- Leutz, W.N., E. Sadowsky, and S. Pendleton. 1992. "Cost Caps in State Long-Term Care Programs." Waltham, MA: Brandeis Institute for Health Policy.
- Levine, M. 1979. "Congress (and evaluators) ought to pay more attention to history." 1-17 In *J Community Psychol (American journal of community psychology)*.
- Levy-Storcks, L., J. F. Schnelle, and S. F. Simmons. 2002. "A comparison of methods to assess nursing home residents' unmet needs." *Gerontologist*. 42:454-61.
- Lyon, S. M. 1997. "Impact of regulation and financing on small board-and-care homes in Maryland." *J Aging Soc Policy*. 9:37-50.
- Maehoney, K. J., S.M. Desmond, L. Simon-Rusinowitz, D. M. Loughlin, and M. R. Squillace. 2002. "Consumer preferences for a cash option versus traditional services: Telephone survey results from NJ elders and adults." *Journal of Disability Policy Studies*. 13:74-86.
- Manard, B. 2002. "Nursing Home Quality Indicators: Their Uses and Limitations." Washington D.C.: AARP Public Policy Institute.
- McCall, N., A. Petersons, S. Moore, and J. Korb. 2003. "Utilization of home health services before and after the Balanced Budget Act of 1997: what were the initial effects?" *Health Serv Res*. 38:85-106.
- McCarty, D., T. Rieckmann, C. Green, S. Gallon, and J. Knudsen. 2004. "Training rural practitioners to use buprenorphine; using The Change Book to facilitate technology transfer." *J Subst Abuse Treat*. 26:203-8.
- McCormick, J. C., and G. S. Chulis. 2003. "Growth in residential alternatives to nursing homes: 2001." *Health Care Financ Rev*. 24: 143-50.
- Mendelson, M.A. 1974. *Tender Loving Greed*. New York: Vintage Books.
- Mercer, S.O., P. Heacock, and C. Beck. 1993. "Nurse's Aides in Nursing Homes: Perceptions of Training, Work Loads, Racism and Abuse Issues." *Journal of Gerontological Social Work*. 21:95-112.
- Miller, N. A., S. Ramsland, and C. Harrington. 1999. "Trends and issues in the Medicaid 1915(c) waiver program." *Health Care Financ Rev*. 20:139-60.
- Mor, V. 2004. "A comprehensive clinical assessment tool to inform policy and practice: applications of the minimum data set." *Med Care*. 42:III50-9.
- Mor, V., J. Angelelli, R. Jones, J. Roy, T. Moore, and J. Morris. 2003a. "Inter-rater reliability of nursing home quality indicators in the U.S." *BMC Health Serv Res*. 3:20.
- Mui, A. C. 2001. "The Program of All-Inclusive Care for the Elderly (PACE): an innovative long-term care model in the United States." *J Aging Soc Policy*. 13:53-67.
- Mukamel, D. B., and C. A. Brower. 1998. "The influence of risk adjustment methods on conclusions about quality of care in nursing homes based on outcome measures." *Gerontologist*. 38:695-703.
- OIG. 1982. "Board and care homes - a study of federal and state actions to safeguard health and safety of board and care home residents." Washington, DC: Office of the Inspector General, DHHS.
- Pacala, J. T., R. L. Kane, A. J. Atherly, and M. A. Smith. 2000. "Using structured implicit review to assess quality of care in the Program of All-Inclusive Care for the Elderly (PACE)." *J Am Geriatr Soc*. 48:903-10.

References

- Palmer, Hans. 1983. "Domiciliary Care: A Semantic Tangle." 437-461 In *Long-Term Care: Perspectives from Research and Demonstrations*, edited by Hans Palmer. Washington, DC: US DHHS: Health Care Financing Administration.
- Mor, V., K. Berg, J. Angelelli, D. Gifford, J. Morris, and T. Moore. 2003b. "The quality of quality measurement in U.S. nursing homes." *Gerontologist*. 43 Spec No 2:37-46.
- Porell, F., and F. G. Caro. 1998. "Facility-level outcome performance measures for nursing homes." *Gerontologist*. 38:665-83.
- Rogers, E. 1983. *Diffusion on Innovations*. New York: Free Press.
- Ryan, J., R. I. Stone, and C. R. Raynor. 2004. "Using large data sets in long-term care to measure and improve quality." *Nurs Outlook*. 52:38-44.
- Salmon, J.R., and L. Polivka. 1998. "Consumer Views of Quality of Life in Long-Term Care." 63-89. In *Voices of Experience: Listening to our Elders*, edited by R. Elsner. Athens, GA: UGA Gerontology Center.
- Sceigaj, M., J. Capitan, and C. Kaye. forthcoming. "Racial/ethnic differences in preferences for consumer-directed care." *The Gerontologist*. September, 2004.
- Schnelle, J. F. 1997. "Can nursing homes use the MDS to improve quality?" *J Am Geriatr Soc*. 45:1027-8.
- Schnelle, J. F., B. M. Bates-Jensen, L. Levy-Storms, V. Grbic, J. Yoshii, M. Cadogan, and S. F. Simmons. 2004. "The minimum data set prevalence of restraint quality indicator: does it reflect differences in care?" *Gerontologist*. 44:245-55.
- Schnelle, J. F., M. P. Cadogan, J. Yoshii, N. R. Al-Samarrai, D. Osterweil, B. M. Bates-Jensen, and S. F. Simmons. 2003. "The minimum data set urinary incontinence quality indicators: do they reflect differences in care processes related to incontinence?" *Med Care*. 41:909-22.
- Schnelle, J. F., D. R. Newman, M. White, T. R. Volner, J. Burnett, A. Cronqvist, and M. Ory. 1992. "Reducing and managing restraints in long-term-care facilities." *J Am Geriatr Soc*. 40:381-5.
- Schnelle, J. F., J. G. Ouslander, J. Buchanan, G. Zellman, D. Farley, S. H. Hirsch, and D. B. Reuben. 1999. "Objective and subjective measures of the quality of managed care in nursing homes." *Med Care*. 37:375-83.
- Schnelle, J. F., J. G. Ouslander, and P. A. Cruise. 1997. "Policy without technology: a barrier to improving nursing home care." *Gerontologist*. 37:527-32.
- Schnelle, J. F., S. Wood, E. R. Schnelle, and S. F. Simmons. 2001. "Measurement sensitivity and the Minimum Data Set depression quality indicator." *Gerontologist*. 41:401-5.
- Shaughnessy, P. W., K. S. Crisler, and R. E. Schlenker. 1998. "Outcome-based quality improvement in home health care: the OASIS indicators." *Qual Manag Health Care*. 7:58-67.
- Shaughnessy, P. W., R. E. Schlenker, K. S. Crisler, A. G. Arnold, M. C. Powell, and J. M. Beaudry. 1996. "Home care: moving forward with continuous quality improvement." *J Aging Soc Policy*. 7:149-67.
- Simmons, S. F., E. T. Garcia, M. P. Cadogan, N. R. Al-Samarrai, L. F. Levy-Storms, D. Osterweil, and J. F. Schnelle. 2003. "The minimum data set weight-loss quality indicator: does it reflect differences in care processes related to weight loss?" *J Am Geriatr Soc*. 51:1410-8.
- Singh, N. 2004. "Improving Quality of Care." Commonwealth Corporation. Available online at <http://www.commcop.org/cre/documents/ResearchBrief2-1.pdf>. Accessed on August 10, 2004.
- Speigel, A. 1983. *Home Healthcare: Home Birthing to Hospice Care*. Owings Mills, MD: National Health Publishing.
- Spore, D. L., V. Mor, P. Larrat, C. Hawes, and J. Hiris. 1997. "Inappropriate drug prescriptions for elderly residents of board and care facilities." *Am J Public Health*. 87:404-9.
- Spore, D., V. Mor, J. Hiris, E. P. Larrat, and C. Hawes. 1995. "Psychotropic use among older residents of board and care facilities." *J Am Geriatr Soc*. 43:1403-9.
- Spore, D., V. Mor, E. P. Larrat, J. Hiris, and C. Hawes. 1996. "Regulatory environment and psychotropic use in board-and-care facilities: results of a 10-state study." *J Gerontol A Biol Sci Med Sci*. 51:M131-41.
- Stone, R. I. 2004. "The direct care worker: the third rail of home care policy." *Annu Rev Public Health*. 25:521-37.
- Stone, R. I., S. C. Reinhard, B. Bowers, D. Zimmerman, C. D. Phillips, C. Hawes, J. A. Fielding, and N. Jacobson. 2002. "Evaluation of the Wellspring Model for Improving Nursing Home Quality." New York: The Commonwealth Fund.
- Thomas, C. P., and S. M. Payne. 1998. "Home alone: unmet need for formal support services among home health clients." *Home Health Care Serv Q*. 17:1-20.
- Thomas, C.P., S. Wallack, D. Hodgkin, J. DiMasi, L. Simoni-Wastila, A. Rader, R. Constantine, and J. Brown. 2000. "Prescription Drug Policy: Background Paper for the Princeton Conference." Brandeis University.
- Thomas, C.P., S.S. Wallack, S. Lee, D. McCarty, and R. Swift. 2003. "Research to practice: adoption of naltrexone in alcoholism treatment." *J Subst Abuse Treat*. 24:1-11.
- Thomas, M. N. 1998. "Understanding Medicare reimbursement." *Home Health Nurse*. 16:840-3.
- Tilly, J., and J. M. Wiener. 2001. "Consumer-directed home and community services programs in eight states: policy issues for older people and government." *J Aging Soc Policy*. 12:1-26.
- U.S. General Accounting Office. 1999. "Nursing Homes: Additional Steps Needed to Strengthen Enforcement of Federal Quality Standards. HEHS-99-46." Washington D.C.: GAO.
- . 2000a. "Nursing Homes: Success of Quality Initiatives Requires Sustained Federal and State Commitment, by William Scanlon, director of health financing and public health issues, before the Senate Special Committee on Aging. T-HEHS-00-209." Washington D.C.: GAO.
- . 2000b. "Nursing Homes: Sustained Efforts Are Needed to Realize Potential of the Quality Initiatives. T-HEHS-00-197." Washington D.C.: GAO.
- . 2002a. "Long-Term Care: Availability of Medicaid Home and Community Services for Elderly Individuals Varies Considerably. GAO-02-1121." Washington DC: GAO.
- . 2002b. "Medicare Home Health Agencies: Weaknesses in Federal and State Oversight Mask Potential Quality Issues. GAO-02-382." Washington D.C.: GAO.
- . 2002c. "Nursing Homes: Federal Efforts to Monitor Resident Assessment Data Should Complement State Activities. GAO-02-279." Washington D.C.: GAO.
- . 2002d. "Nursing Homes: Public Reporting of Quality Indicators Has Merit, but National Implementation Is Premature. GAO-03-187." Washington D.C.: GAO.
- . 2002e. "Nursing Homes: Quality of Care More Related to Staffing than Spending. GAO-02-431R." Washington D.C.: GAO.
- . 2003a. "Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should be Strengthened. GAO-03-576." Washington D.C.: GAO.
- . 2003b. "Nursing Homes: Prevalence of Serious Quality Problems Remains Unacceptably High, Despite Some Decline. GAO-03-1016T." Washington D.C.: GAO.
- Vladeck, B. 1980. *Unloving Care: The Nursing Home Tragedy*. New York: Basic Books.
- Wagner, E. H., B. T. Austin, and M. Von Korff. 1996. "Organizing care for patients with chronic illness." *Milbank Q*. 74:511-44.
- Weech-Maldonado, R., L. Meret-Hanke, M. C. Neff, and V. Mor. 2004. "Nurse staffing patterns and quality of care in nursing homes." *Health Care Manage Rev*. 29:107-16.
- Weissert, W. G., C. M. Cready, and J. E. Pawelak. 1988. "The past and future of home- and community-based long-term care." *Milbank Q*. 66:309-88.
- Wiener, J. M. 2003. "An assessment of strategies for improving quality of care in nursing homes." *Gerontologist*. 43 Spec No 2:19-27.
- Wiener, J. M., C. L. Estes, S. M. Goldenson, and S. C. Goldberg. 2001. "What happened to long-term care in the health reform debate of 1993-1994? Lessons for the future." 207-52, IV In *Milbank Q*.
- Wiener, J. M., and D. G. Stevenson. 1998. "Repeal of the "Boren Amendment": Implications for Quality of Care in Nursing Homes." Washington D.C.: The Urban Institute.
- Wipke-Tevis, D. D., D. A. Williams, M. J. Rantz, L. L. Popejoy, R. W. Madsen, G. F. Petroski, and A. A. Vogelsmeier. 2004. "Nursing home quality and pressure ulcer prevention and management practices." *J Am Geriatr Soc*. 52:583-8.
- Wolfe, W. 1999. "Nursing Homes Shake Off Old Role as Place Only for Death." *Minneapolis Star Tribune*. Minneapolis.
- Yee, D. L., J. Capitan, W. N. Leutz, and M. Sceigaj. 1999. "Resident-centered care in assisted living." *J Aging Soc Policy*. 10:7-26.
- Zimmerman, D. R., S. L. Karon, G. Arling, B. R. Clark, T. Collins, R. Ross, and F. Sainfort. 1995. "Development and testing of nursing home quality indicators." *Health Care Financ Rev*. 16:107-27.