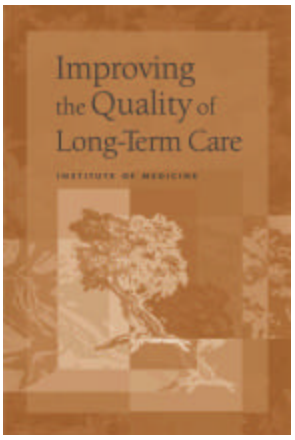
INSTITUTE OF MEDICINE

Shaping the Future for Health

IMPROVING THE QUALITY OF LONG-TERM CARE



Serious concerns persist about the quality of long-term care among policymakers and the public, including the users of the services and their families. Despite some improvements in recent years, nursing homes in particular remain the focus of continuing concern about the quality, cost, and accessibility of care and the adequacy of oversight and enforcement mechanisms. Debate also continues over the effectiveness and appropriate scope of state and national policies to regulate long-term care, reduce poor performance of providers, and improve the health and well-being of those receiving care. These questions and debates extend beyond nursing homes to home and community-based services and residential care facilities.

Who Uses Long-Term Care?

Long-term care covers a diverse array of services provided over a sustained period of time to people of all ages with chronic conditions and functional limitations. Their needs range from minimal personal assistance with basic activities of everyday life to virtually total care and are met in a variety of care settings such as nursing homes, residential care facilities, or people's homes. Of the 190 million people aged 18 years of age and older in 1994, nearly 9 million were using long-term care. Of these, 6.5 million were over 65 years and older. Elderly people using long-term care are more likely to be women, to be cognitively impaired, and to have a greater number of limitations with activities of daily living. The aging of the U.S. population and the projected growth of the oldest age bracket (85 years and older) will have a major effect on the demand for and supply of long-term-care services and on the resources needed to provide those services. The implications of these changes are enormous, as evidenced by the widespread public and policy focus on the elderly population in discussions of such care.

Although "long-term care" conjures the image of an elderly person in a nursing home, it is not limited to the needs of older persons or to care provided in nursing homes. The number of children and adolescents with severe long-term health conditions, although small in comparison to the elderly, has grown substantially over the past two decades and will continue to do so. Advances in medicine and surgical technologies now allow many children who would have died in previous eras to survive to adulthood, although often with psychological and physical impairments. Others using long-term care include adults with physical and developmental disabilities.

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In 1986, the Institute of Medicine (IOM) Committee on Nursing Home Regulations issued its report *Improving the Quality of Care in Nursing Homes.*

Its recommendations provided the basis for Congress to enact in 1987 a major reform of nursing home regulations. Since the IOM issued its 1986 report, many changes have occurred. For instance, long-term care is no longer synonymous with nursing home care. The use of alternative, noninstitutional settings for long-term care has increased and now includes home health care, personal care, residential care, and other services.

In the context of these evolving long-term-care needs, options, and persistent concerns about the quality of long-term care, the Robert Wood Johnson Foundation requested that the IOM examine the quality of long-term care provided in nursing homes and other long-term-care settings. The Archstone Foundation, the Irvine Health Foundation, the Department of Veterans Affairs, and the Health Care Financing Administration provided additional support.

Committee's Findings and Recommended Remedies

In reviewing the information and data available, the IOM Committee on Improving the Quality of Long-Term Care noted many problems, including the following:

> It is easier to propose a comprehensive examination of long-term care than to identify, collect, and analyze relevant data to support comparable descriptions and assessments across the diverse settings, services, and populations.
>
> Defining or evaluating quality of long-term care is fraught with problems, made more difficult by the unevenness of the available empirical evidence. Information to evaluate quality of care in nursing homes is extensive and systematic, but for most other settings it is nonexistent or very limited and lacking in uniformity.

Throughout the study, the committee's work on several of the issues it was asked to examine was impeded by the lack of common definitions to describe many of the providers of long-term care and the lack of comprehensive, timely, and reliable data across and within states and settings. What information is available often is not comparable and does not take into account how people perceive their experience of long-term care.

Status of Quality in Long-Term Care

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The quality of care in nursing homes may have improved in some areas during the past decade even though nursing homes are serving a more seriously ill population. This improvement to a large extent is due to provider response to the 1987 Nursing Home Reform and the forces that gave rise to this legislation. Improvements are best documented for the use of physical and chemical restraints in nursing homes. The quality of life for nursing home residents also has shown some improvements, but to a lesser extent. However, serious problems concerning quality of care apparently continue to affect residents of this country's nursing homes, and persistently poor providers of care are still in operation. Pain, pressure sores, malnutrition, and urinary incontinence have all been shown to be serious problems in recent studies of nursing home residents.

Outside of nursing homes, very little is known about the quality of care or outcomes of services provided by medically oriented home health agencies, and even less is known about the quality of social service-oriented home and community-based services. Residential care facilities, including assisted living, present a mixed picture in terms of both quality of care and quality of life. Some offer individualized, high-quality care in facilities that afford privacy, dignity, and individualization. However,

others appear to lack adequately trained staff and offer neither a sufficient amount of care nor privacy and "homelike" settings. In addition, there are indications that consumers may receive too little information to make informed choices regarding these facilities and the services they provide.

Despite periodic reports about poor conditions in some residential care settings and fraud in sectors of the home health care industry, comprehensive information about quality of care is scarce for the home and community-based services that are preferred by many users of long-term care and their families and advocates. Informed choices about long-term-care alternatives depend on better information. Therefore, the committee recommends that:

- **State agencies and the private sector should disseminate information to consumers on the various types of long-term-care settings available to them and where applicable, information on the compliance of providers with relevant state standards.**

Access to Appropriate Services

Access to home and community-based services—especially personal care services for people with disabilities—is not uniformly available across states. 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. **The Health Care Financing Administration and state governments should undertake research toward developing an appropriate array of community-based long-term-care services to meet the needs of consumers and assess the quality of the services and outcomes.** At the same time, access to and choice of appropriate services are essential to quality of care and quality of life for individuals with disabilities.

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Moving toward meaningful consumer-centered services in long-term-care settings would require a mix of changes in consumer and provider attitudes, business practices, public policies, care processes, and management structures. Achieving such changes requires research, time, and effort to integrate the elements of consumer-centered care into the training and attitude of the full range of paid caregivers.

The range of benefits, risks, and resources associated with different approaches to consumer-directed personal care services for people with disabilities is only beginning to be identified. Before these principles could be translated into workable and cost-effective programs, developmental and feasibility research and evaluation is needed in several areas.

- **The Department of Health and Human services, with input from states and private organizations, should develop and fund a research agenda to investigate the potential quality impact associated with access to, and limitations of, different models of consumer-centered care services including consumer directed services.**

Monitoring and Assuring Quality Standards

Federal and state governments share regulatory responsibilities for long-term care. Overall, the federal government has a dominant presence in nursing home and home health regulation through certification for Medicare and Medicaid participation. States, however, play the major role in regulating other kinds of long-term care and have broad discretion in carrying out this oversight.

Serious deficiencies remain in the implementation of government programs to assess and enforce basic standards of quality in long-term care. At the federal level, a number of technical and methodological challenges exist in using the information gathered in the data systems developed to provide basic information on monitoring compliance by nursing homes with regulatory standards. Although the basic standards for nursing homes are sound, the surveying and enforcement of the standards has been weak, with widespread variability across states.

The information base available for nursing homes suggests a number of problems including variation in state survey and enforcement processes, restricted federal funding for state programs, and inadequate attention to home and community-based services. Particularly worrisome is the continued participation in Medicare and Medicaid of persistently poor-performing providers, especially those who have been repeatedly dropped from the program and reinstated. The Health Care Financing Administration has announced several initiatives to improve specific areas of weakness, but Congress and advocacy groups should continue the monitoring of their implementation and consequences.

- **Some of the changes recommended to improve the regulatory system include targeting chronically poor-performing providers, increasing penalties for repeat violations of standards, decertifying persistently substandard providers and greater uniformity in surveyor interpretation and application of survey regulations.**

Other changes identified include paying more attention to chain facilities, focusing on residents' problems, improving sampling techniques and sample sizes, strengthening the consistency of survey determinations, improving complaint investigations, and certifying the accuracy of nursing home data.

For other types of long-term-care settings, the nature of the information collected by states varies enormously both across and within states; although all states use assessments to develop a care plan, the comprehensiveness of the assessment varies and most states do not have standardized terms. In addition, most states do not require training in the administration of the instrument, despite its importance.

Interest is increasing in the possibility of identifying an instrument or a set of core data elements that is applicable to all users of long-term care. Much work is needed to (a) examine the diversity across states of the services provided, service settings and service arrangements, and the infrastructure for monitoring quality, and (b) then to develop agreements on common core data elements and uniform definitions of various community-based arrangements across states.

- **The Department of Health and Human Services and other organizations should fund research to further develop quality assessment instruments that can be used across different settings and with different population groups.**

Unresolved questions remain about the appropriate role of state regulatory standards in meeting the needs and preferences of the diverse population using long-term care.

Little information is available about federal or state performance in monitoring the quality of long-term care provided under Medicaid's home and community-based services waiver program. To guide decisions, policymakers need more information about how the program is working and, more generally, about how states are defining and regulating community-based long-term-care services and supportive housing for different populations. Unresolved questions remain about the appropriate role of state regulatory standards in meeting the needs and preferences of the diverse population using long-term care. Research studies have raised serious questions about the effectiveness of state regulation and licensure promoting quality in residential care.

Concerned about reports of quality problems in community-based residential care, the committee pointed to a range of actions that might help improve state-level regulation.

- **Research is needed to examine the effectiveness of state survey and enforcement activities, especially in terms of quality of care, quality of life, staffing, and other measures related to residential care.**
- **All states should have appropriate standard-setting and oversight mechanisms for all types of settings in which people receive personal care and nursing services.**
- **Effective consumer advocacy and protection programs should be encouraged and funded to support consumer education and information dissemination and complaint resolution programs and processes targeted at consumers of community-based long-term-care services.**

Strengthening the Caregiving Workforce and Organizational Capacity

Long-term-care services are labor intensive, and therefore the quality of care depends largely on the performance of the caregiving personnel. Personnel standards vary considerably across long-term-care settings. Federal standards have been set for some personnel in nursing homes and home health agencies, but not for personnel providing care in other types of long-term-care settings. Some states also have their own requirements for personnel in the facilities and programs that they regulate, particularly regarding health professionals and long-term-care administrators, but these requirements vary widely across states.

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A slight but noticeable increase in staffing level has occurred in recent years. This increase may be attributed in part to the requirements of the 1987 nursing home reform and in part to the increased acuity of residents and the consequent staffing required to provide specialized services. The committee found a wide range of staffing levels in nursing facilities. Many facilities have adequate staffing levels and provide high-quality care to residents. Current staffing levels in some facilities are not sufficient to meet the minimum needs of residents for provision of quality of care, quality of life, and rehabilitation. Research provides abundant evidence of quality-of-care problems in some nursing homes, and such problems are related in part to inadequate staffing levels.

The 1996 IOM study, requested by Congress to examine the adequacy of nurse staffing in hospitals and nursing homes, found that a positive relationship exists between nursing staffing and quality of care and that trends in resident characteristics suggest an increasing need for professional nursing presence. It further concluded that there was abundant evidence that participation of professional nurses in direct caregiving and provision of hands-on guidance to nursing assistants in caring for residents is positively associated with quality of care. That report recommended that more registered nurses be added to the staff in nursing homes and that by the year 2000, a 24-hour presence of registered nurse coverage in nursing facilities be required as an enhancement to the current 8-hour requirement specified under OBRA 87.

- **This IOM committee concurs with the 1996 report and recommends that the Health Care Financing Administration implement the 1996 IOM recommendation to require the presence of a registered nurse 24 hours a day. It further recommends that HCFA develop minimum staffing levels (both number and skill mix) for direct care based on case-mix-adjusted standards.**

Many factors influence the quality of care provided to residents by staff and the quality of life of the residents. Staffing levels and staff characteristics are critical structural elements. Nurse staffing levels alone are a necessary, but not a sufficient, condition for positively affecting care in nursing homes. Education and training of staff, supervision, environmental conditions, attitudes and values, job satisfaction and turnover of staff, salaries and benefits, leadership, management, and organizational capacity are all essential elements affecting quality of care to residents.

Efforts to improve the quality of long-term care therefore require a workforce that is sufficient in size, with the necessary skills, competence, and commitment to provide the needed health and personal care services and to manage the delivery of this care in a supportive environment. This committee has serious concerns about each of these requirements and believes that numbers, skills, training, assessment, and positive management of frontline caregivers must become a higher priority for policymakers, managers, advocacy groups, health professionals, and researchers. The committee therefore recommends that:

- **All long-term-care settings, as well as governments and providers, in consultation with consumers, should develop appropriate training, education, and competency standards and training programs for staff.**
- **Federal and state governments, as appropriate, should undertake—for all long-term-care workers and for all settings—measures to improve work environments including competitive wages, career development opportunities, work rules, job design, and supervision that will attract and retain a capable, committed work force.**
- **Congress should require timely performance of criminal background checks before hiring for all personnel in all long-term-care settings in order to avoid hiring those convicted of a felony or any crime involving the abuse, neglect, or exploitation of others.**

However, increasing staffing without simultaneously improving management systems will most certainly result in less-than-expected improvement. Technical expertise, staff resources, and good management are essential to make the most of increased staffing.

- **The Department of Health and Human Services should establish Centers for the Advancement of Quality of Long-Term Care and initiate research, training, and demonstration programs for providers to redesign care processes consistent with best practices and improvements in quality of life.**

Substantial improvements in the long-term-care workforce are not possible without increased resources for providers of care. Government policies of reimbursing for long-term care have an important influence in improving quality of care. Recognizing that its recommendations would entail additional costs for providers of care,

- **The committee recommends that Congress and state Medicaid agencies adjust their Medicaid reimbursement formulas for nursing homes to take into account any increases in the requirements of nursing time to meet the case-mix-adjusted needs of residents.**

Reimbursing to Improve Quality of Care

The amounts and ways we pay for long-term care are probably inadequate to support a workforce sufficient in numbers, skills, stability, and commitment to provide adequate clinical and personal services for the increasingly frail or complex populations using long-term care. The information available to the committee on staffing levels and skills, management, training, wage levels, working conditions, and turnover suggests that resource constraints are a serious problem. This situation has important implications because the long-term-care workforce is the essential pathway to many improvements in processes of care based on better understanding of care processes and outcomes, internal quality improvement strategies, and more effective regulation.

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Few efforts have highlighted the role that reimbursement can play in promoting or inhibiting the quality of long-term care. Contributing to the lack of emphasis on reimbursement is the paucity of conclusive data on the subject. Some studies have linked diminished quality of care in nursing homes to low Medicaid payment rates, but others have posited that quality-of-care deficiencies should be attributed to factors such as excess demand. Relatively little is known about the effect of reimbursement on quality of care in nursing homes, and virtually nothing is known about its impact on home and community-based services.

Research is lacking in understanding the effect of changes in payment policies on providers, on accessibility of services, and on the quality of care. What exists is limited to nursing homes, is based on old data, and does not reflect the regulatory changes enacted in 1987. Although there does not appear to be a simple relationship between cost and quality, logic suggests that there is some minimal level of reimbursement below which it will be either difficult or impossible for nursing homes to provide an adequate level of care. Recent changes in payment policies combined with large budget cuts have created turmoil in the long-term-care sector and highlighted the need for research in this area.

- **Before making decisions to reduce reimbursements, state officials should carefully assess the impact on access to services and on quality of care of any proposed reductions in reimbursements.**
- **The Department of Health and Human Services should fund and support research to better understand the effects of payment policies on accessibility and quality of long-term-care services.**

In closing, the committee hopes that its findings and conclusions will provide some insights for the current discussions on policies for meeting the care needs of long-term-care users. With hope, it will lead to the needed research and data collection for obtaining a comprehensive and reliable description of the various long-term-care arrangements throughout the country, their size, the services provided and staffing levels and training, the characteristics of those receiving care, and the staffing and quality of care provided in the different settings and services. Regardless of the approach to long-term care adopted, the importance of reliable and timely data on which to base decisions cannot be understated. Such information is essential for policy development and evaluation of long-term care in the United States.

For More Information . . .

Copies of *Improving the Quality of Long-Term Care* are available for sale from the National Academy Press; call (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area), or visit the NAP home page at **www.nap.edu.** The full text of the report is available on line at **books.nap.edu/catalog/9611.html.**

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