

Chapter 10

Quality Assurance in Long-Term Care: Special Issues for Patients With Dementia

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Quality Assurance in Long-Term Care: Special Issues for Patients With Dementia*

With a burgeoning population of elderly individuals at risk of needing long-term care, the most rapidly increasing inflation ever in the health care sector, and continuing scandals about substandard care, the Nation's long-term care program faces serious challenges. It faces the demand for more and better nursing home care and an expanded, effective range of alternatives to institutional care. It also faces significant fiscal constraints, as growth in expenditures threatens to undermine the fiscal viability of Medicare and to bankrupt State budgets that provide a share of Medicaid funds. It faces the challenge of eliminating discrimination against individuals most in need of competent and caring long-term services—the “heavy care” patients who require substantial supervision and “hands-on” care (particularly individuals with dementing illnesses), and those individuals, impoverished by age and illness, who must rely on Medicaid for assistance in paying for nursing home care.

Despite considerable improvement, inadequate quality of long-term care nationwide remains a serious problem. These failings are the product of many factors and exist despite government regulation. In general, the regulatory system for institutional care is criticized for having inadequate and inappropriate standards, an ineffective monitoring or inspection system, and insufficient compliance mechanisms for enforcing even minimal standards. For noninstitutional long-term care, quality assurance is in its infancy, with less well-developed standards, more significant monitoring problems, and a general absence of compliance mechanisms and remedies for inadequate care or services.

● This chapter is based largely on a contract report by Catherine Hawes and research assistant Linda L. Powers, Center for Social Research and Policy Analysis, Research Triangle Institute, Research Triangle Park, North Carolina.

These problems reflect difficulties in regulating services like home health care, home chore assistance, and respite care in standard ways. Many programs are so small or localized that regulatory controls could appear cost-ineffective or impractical. Complex regulatory requirements could act as a disincentive to individuals offering these services, thereby undermining efforts to encourage further development of noninstitutional care. Nonetheless, formal delivery of long-term care services in noninstitutional settings creates a need for some mechanism to assure the delivery of quality care.

Policymakers seeking to assure high-quality long-term care must consider three major questions: What are the appropriate goals for long-term care? How can quality be measured and assessed? And how can its provision be assured? This chapter examines the problems and issues involved in assuring quality long-term care, with a special focus on the care needs of individuals with a dementing disorder,

The first section of the chapter describes major conceptual issues in defining and measuring quality in long-term care. The second section discusses problems in long-term care quality, describes the current regulatory system, and presents major criticisms of the standards, inspections, and enforcement mechanisms for assuring acceptable quality. The final section suggests mechanisms for improving quality in long-term care during an era of fiscal constraints.

Much of the chapter focuses on quality assurance in nursing homes, as public policy currently has a more extensive role in paying for *and* establishing standards in these settings. Some discussion of quality assurance for other long-term care services (e.g., adult day care, respite care, home health services) is included.

DEFINING QUALITY IN LONGTERM CARE

The first step in assuring delivery of quality care is to define the term "quality." The customary emphasis on the effect of care on a person's physical health is difficult to apply in the case of those needing long-term care. Long-term care is aimed at persons with diseases and disabilities that are chronic and often degenerative. It typically encompasses both health care and social support services that enable an individual and his or her family to cope with multiple impairments over time, but cure is rarely a feasible objective.

The Relevant Domains of Long-Term Care Quality

From a quality assurance perspective, quality in long-term care revolves around two principal factors: the characteristics of individuals, and their care needs. A salient characteristic of most people needing long-term care is the multiplicity of their impairments. The average nursing home resident, for example, is an 83-year-old widow suffering from three or more chronic diseases and disabilities (174). Individuals residing in domiciliary care facilities (DCFs) (e.g., board and care homes) also have multiple physical and mental impairments. And older persons who use other long-term care services commonly also have multiple chronic diseases and disabilities that interfere with their ability to function independently. These individuals differ in many ways, such as in their informal supports, the type and severity of primary medical conditions, and the length of time they require care. However, they have a number of important similarities that are central to a definition of long-term care quality:

- They require services that may involve care of acute or subacute illness but in which chronic care needs predominate.
- They have multiple diseases and disabilities for which care and services are needed. Medical diagnosis is but one component of assessing their care needs.
- Their physical, mental, and social well-being are closely related—mental and emotional status both affect and are affected by physical health. Substantial research indicates that

environments that foster autonomy, integration, and personalized care are related not only to satisfaction but to improved health outcomes (16,35,83)131). Social isolation is associated with declining physical health status and premature mortality (9,60,61,125).

- They can benefit from efforts to improve, maintain, or prevent decline in physical functioning. The ability to function more or less independently in activities of daily living, despite disease and disability, is central to individuals' well-being.

Quality of long-term care is thus a complex and multidimensional concept. Long-term care should address the physical, functional, mental, and emotional needs of individuals with multiple chronic diseases and disabilities. Moreover, it should be aimed not only at improving individuals' physical health, but also at enhancing the quality of their daily lives (126). Even if the relevant dimensions of appropriate long-term care are known, however, evaluating the quality of care provided can be an elusive goal.

Difficulties in Defining Quality

An inherent difficulty in defining quality involves the multidimensionality of long-term care. For many individuals, achieving one aspect of high-quality long-term care may impinge on another aspect. Take the case of an elderly woman whose mobility is slightly impaired but who enjoys walking about a nursing home unattended, valuing control and autonomy in this small area of her life. Because the woman is somewhat unsteady on her feet and has had one fall, the nursing home staff and her physician feel that she should be prevented from walking around without a staff member to assist her. Because she resists this suggestion, she is frequently restrained. The goal of the nursing home and physician is to prevent a negative health outcome—a fall, and possible serious complications. Yet the impact, from the resident's perspective, is to seriously erode personal control, freedom, and quality of life. Complicating the situation is the fact that her enforced immobility may contribute to further loss of func -

tional ability and to other adverse conditions, such as skin breakdown and pneumonia.

This hypothetical case illustrates the potential in long-term care for direct conflict between one aspect of quality and another—an incompatibility seen most clearly in relation to quality of life issues. It points out that quality of care is not necessarily synonymous with quality of life (120).

Another difficulty in establishing a single definition of long-term care quality involves the variability of individual needs and preferences. What is high quality for one patient may not be for another. Moreover, those who provide long-term care and those who receive it often differ in their concept of what constitutes high-quality care. The views of health care professionals and providers have dominated in the delivery of services, despite indications that they may differ from the views of patients. In one study, nursing home residents, their families, nursing home administrators, nurses, and other staff were asked to identify factors that best capture their concept of quality (43). The study demonstrated that the relative importance of various components varies from group to group:

- Nursing home administrators responded that “self-worth” was the most salient aspect of quality, with lighting and environmental stress as the two other most important dimensions.
- Families chose resident treatment plans, preventive health care, and recreational activities as the three most significant dimensions of quality.
- Residents rated personal identity as the most important component of overall quality, with food appeal and staff attitudes as the other two most important dimensions.

In short, there is no simple, elegant way to define quality or to determine objectively the extent to which all of its many facets are present. For purposes of quality assurance, therefore, quality must be defined in relation to those things that can be reliably measured and that a quality assurance system can reasonably achieve.

Measuring Quality of Care

One model for assessing quality that has received considerable attention identifies three aspects of health care to be evaluated—input, process, and outcome measures of quality (46):

1. Inputs and structural components of care describe the quantity and quality of resource inputs (e.g., personnel, services, and equipment), as well as structural variables that characterize the environment in which care is provided. Current Federal standards and licensure laws are based largely on such measures.
2. Process measures encompass the activities or procedures involved in actually providing care. Process-based quality is typically defined in terms of commonly accepted professional norms or standards regarding the types of services and procedures individuals require based on an assessment of their needs. The evaluation of process focuses on whether appropriate services are provided and on the manner in which they are performed.
3. Outcome measures of care focus on positive and negative personal characteristics that can be attributed to the care provided (47). The argument for using outcomes to define and measure quality of care is based on the premise that the ultimate goal of health care systems and procedures is improving or maintaining individuals' health. Proponents argue that outcome measures form the conceptual basis for defining quality and that outcomes are the ultimate validation of all other possible measures of quality (26,27,46,78)88,90) 148).

There has been considerable debate over which way of conceptualizing and measuring quality—input, process, or outcome—is most appropriate for long-term care (3,103)110,1 11,188). Most observers argue against relying totally or largely on input measures and are critical of regulations and research that do (88)97)132). Proponents of outcome measures argue that focusing on outcomes

avoids arguments about which processes and inputs are most effective by letting the results—individual outcomes—speak for themselves. Further, a focus on outcomes might allow providers and policymakers flexibility in determining the most cost effective means of achieving the desired outcomes.

Specifying appropriate and achievable outcomes for recipients of long-term care is beset with conceptual and measurement problems, however:

- Outcomes used in most health care evaluations, such as mortality, rehabilitation, and discharge, may be incomplete or inapplicable for long-term care (85,96,103,160).
- Information about appropriate or achievable outcomes is scarce and inconclusive (96).
- Accuracy of prognostic judgments—expected outcomes—is quite low for long-term care. One study reported only 50 percent accuracy in prognostic judgments regarding expected changes in functional status (191).

Thus, a major task is to identify realistic, achievable outcomes for individuals needing long-term care.

Perhaps the most significant limitation of using outcome measures as regulatory standards is the difficulty in relating individual outcomes to the structure and process of care received (96). Even care of outstanding quality (by input/structure or process standards) does not always produce favorable outcomes. For most individuals needing long-term care, the enormous range and complexity of individual health problems, the limitations of medical knowledge about the course and care of chronic degenerative diseases, and the effect of individual characteristics are such that negative outcomes such as death or deterioration in function often cannot be prevented—no matter how skilled and extensive the care provided (160).

Use of outcome measures for regulatory purposes thus requires that regulators have substantial information about the impact of variables beyond a provider's control. Outside variables to be considered include recipients' characteristics (e.g., age, sex, diagnosis, and functional disabilities) and their effect on outcomes of care. Further, the degree to which the course of chronic diseases and

disabilities can be predicted, given prescribed care of acceptable quality, must be considered. Without awareness of these factors, a definition of quality, sets of criteria, and regulatory requirements based solely on desirable individual outcomes would be unworkable and unrealistic (66,96).

These difficulties are particularly pronounced when attempting to define quality and developing outcome-oriented measures of care for persons with dementia. Although evidence indicates that the rate of deterioration can be moderated through a strong social and medical support system, statistically significant associations between the process of care and individual outcomes have not been established. Variability in the speed and course of individual cases of dementia makes it difficult to specify outcomes as measures of quality. Again, many of these variables appear to be unrelated to the quality of care received. In addition, the chronic, degenerative nature of dementia disorders makes traditionally used health outcome measures inappropriate indicators of quality.

The fact that there are difficulties in specifying appropriate, achievable outcomes does not mean that quality assurance systems—whether regulatory or voluntary—cannot specify some outcome-oriented, recipient-focused measures of quality. These can be developed, and providers can be more effectively monitored and held accountable for the care individuals receive. Outcome-oriented measures may be most applicable to long-term care in nursing homes, since these providers generally oversee a greater portion of recipients' lives than nonresidential care providers do. However, outcome measures also have potential for use in other settings (e.g., home care).

Measures of individual status and process quality that are related to care received and are relevant for persons with dementia are discussed later in this chapter. Many of the outcome-oriented measures discussed in the next section apply primarily to monitoring nursing homes. Because day care, respite care, and home care are usually limited to one type of intervention and occur for only a limited time each day or week, attributing outcomes solely to the quality of a provider's care or services is difficult. For such long-term care services, outcome measures that are problem-

specific and related directly to the care provided are more appropriate. These are discussed later in this chapter.

Developing Outcome Measures of Quality

Monitoring positive outcomes, such as curing infections and decubiti (bedsores), restoring physical functioning, and minimizing deterioration, might be appropriate for evaluating the performance of long-term care providers. Alternatively, a system like that in New York, focusing on preventable negative outcomes or “sentinel health events”) could be useful. This section identifies examples of process and outcome-oriented indicators of poor quality care that are particularly appropriate for persons with dementia.

- **Dehydration and Malnutrition:** These are outcomes that are not only considered undesirable but also generally preventable. Dehydration, for example, has been suggested as an indicator of poor quality care or sentinel health event—a generally preventable negative outcome (54,69,107,149). The condition usually indicates inadequate attention to fluid intake, and thus may serve as a measure of a facility’s provision of care (69). Monitoring the occurrence of dehydration may be particularly relevant for persons with dementia, who may neglect or be unaware of their need for fluids. Dehydration can worsen the mental condition of someone with a dementing illness (92).

Malnutrition is another generally reliable outcome measure of quality. In most cases, unexplained and excessive weight loss or gain is an indicator of inadequate dietary services. The situation for someone with dementia, however, is more complex. In the second stage of Alzheimer’s disease, for instance, people often experience motor hyperactivity. Even when adequate nutrition and meal assistance or supervision are provided, some individuals lose weight and become emaciated (13,44,68), and may be misinterpreted as a result of inadequate nutrition. Thus, if malnutrition is used as an outcome quality measure, surveyors must carefully consider residents’

characteristics in conjunction with dietary services.

- **Drugs and Medications:** Excessive use of psychotropic drugs, medication errors, and adverse drug reactions among nursing home and board and care residents have been cited as common problems and examples of poor quality of care (14,74,84,142,144,145,179, 197). For persons with dementia, such medication errors and overreliance on psychotropic drugs are particularly troublesome. Sedatives, blood pressure drugs, and heart medications are just a few of the medications that can worsen the functional capacity of such individuals (92, 140). Further, because reports indicate that some facilities rely on chemical restraints as a substitute for staff and on psychotropic to control wandering and other behavioral problems associated with dementia, excessive use of psychotropic and adverse drug interactions may be useful quality-of-care measures.

Protocols or process standards for proper use of psychotropic drugs and survey procedures for monitoring facility performance have been developed and could be incorporated in regulations and in a revised Federal certification process (21,94,99, 130, 156).

- **Decubitus Ulcers:** Another potential indicator of poor quality of care is the development of decubiti (bedsores), particularly as residents become less mobile (117,198). Protocols have been developed for identifying and measuring the severity of such skin breakdowns and pressure sores (100,117,130). For physically dependent residents (e.g., those who are bed- and chair-fast), the outcome measure would be the incidence and severity of decubiti. Surveyors would have to determine whether the decubiti occurred while the individual was in the nursing home, and whether, given the resident condition, the development or worsening of the decubiti was avoidable.
- **Urinary Incontinence, Urinary Tract Infections, and Overuse of Indwelling Catheters:** Urinary incontinence is common in the later stages of many dementing illnesses. When it develops, however, a medical evaluation is indicated. Potentially treatable causes

(e.g., infections or an enlarged prostate gland may be found. Numerous strategies exist to manage incontinence due to Alzheimer's disease, and standards can be developed for proper treatment of the condition. Fluid restriction is not an acceptable treatment for urinary incontinence (92).

Another indicator of quality might be the use of indwelling catheters as opposed to bladder training programs and staff attention for management of incontinence. Many view the excessive use of indwelling catheters as a sign of poor care, and process standards have been developed for their proper use (22,57,118,130,135,192,198). Among nursing home residents who have indwelling catheters, the development of infections is also a sign of poor care (57,80,135,136,139). One measure of outcome quality, therefore, would be the incidence of urinary tract infections among residents who are catheterized.

- **Restraints:** Use of physical and chemical (psychotropic drugs) restraints to control disruptive behavior (e.g., wandering, screaming, or agitation) among residents with dementia may indicate inadequacies in provision of care. Where restraints are used as a substitute for staff supervision, activities, and treatment, they may be considered a negative outcome or sentinel health event, preventable through appropriate care. Guidelines for the use of restraints, which can be developed as appropriate process standards of care, have been suggested (42).
- **Nursing and Personal Care** These are very relevant to the quality of life experienced by nursing home residents, and to their sense of well-being, satisfaction, and mental and social functioning (15,62). The Iowa Department of Health, for example, evaluates 17 nursing and personal care services as part of each facility's licensure survey (21,99). Two other instruments also assess personal care and grooming, New York's Sentinel Health Events (11), and one used by the Kane Group (89). These could be used to develop standards for appropriate personal care and grooming outcomes.

For residents with dementia, interviews may not be feasible, but direct observation

may be an effective way to determine the quality of their personal care. observations could focus on such things as cleanliness of resident's clothing and oral and physical hygiene (e.g., hair and nails). Surveyors might also observe such features as the promptness with which call lights and other resident requests for assistance are acknowledged, cleanliness of assistive devices (e.g., indwelling catheter tubes), and the manner in which personal care is delivered.

- **Mental Status:** The need for greater attention to mental health aspects of care, including appropriate assessment and management techniques for mental and behavioral problems and specialized activities programs, is well documented (25,152,175,199). The two most frequent diagnoses among nursing home residents are depression and intellectual impairment (e.g., organic brain syndrome, confusional states, or dementia) (25,178,199). Appropriate treatment is essential since depression, demoralization, and social isolation have been measured and associated with social functioning (18,62), physical health status, premature mortality (9,61), and activity levels (98). Moreover, particularly for depression, elderly individuals are at least as responsive to psychiatric treatment as other groups (36). Although it is not known how measurement of cognitive or behavioral factors can be incorporated into assessments of quality, it is clear that these factors are important.
- **Quality of the Living Environment:** This is a prime component of residents' definition of quality (126). Quality of the living environment includes residents' physical safety, facility cleanliness, and comfort (e.g., the ability of residents to have personal possessions and furnishings in their rooms). Standards could define expectations for the condition of residents' rooms, bathrooms, and common areas. Inspections could focus on such "outcomes" as safety, sanitation, and comfort. The Iowa instrument, mentioned above, provides a scoring procedure for evaluating several aspects of the living environment in nursing homes. A similar instrument could be developed for board and care facilities.

In summary, outcomes representing changes in patient status over time and those representing “benchmark” indicators of quality can serve as measures of quality of care. More often, however, given the current paucity of knowledge about expected outcomes for persons with dementia and the complex relationship between individual’s characteristics, treatment interventions, and

health outcomes, outcome measures might more appropriately be used as potential indicators of poor quality of care. Negative outcomes that appear to have been preventable could prompt examination of facility process and structure. The development of appropriate process and structural standards to define acceptable quality of care is discussed later in this chapter.

THE FAILURE TO ASSURE ACCEPTABLE QUALITY IN LONG-TERM CARE

Long-term care has been provided, with more or less skill and resources, in various forms for decades—first in mental institutions, poorhouses, and poorfarms, and later in converted houses, farms, and motels. Home health care, by visiting nurses or by “practical nurses” hired by families, also has a relatively long history. But significant expansion of formal long-term care services really began only within the last quarter-century, particularly since the passage of Medicaid in 1965. Institutional long-term care, primarily in nursing homes, was the first to flourish under these new payment systems. Home health care, home chore services, adult day care, and respite care have emerged much more recently, and their services and quality assurance systems are both in their infancy, as noted earlier. A common factor for all these long-term care services is the difficulty of ensuring or measuring the delivery of quality care.

Concern About Quality

Concern about quality of long-term care arises from a variety of factors:

- **Demographics:** An increasing number of elderly persons will require some form of long-term care, and those at risk of needing long-term care are rapidly growing in number, as described in chapter 1.
- **Debilitation of Patients:** Evidence suggests that individuals seeking nursing home and home health services are increasingly frail and disabled. The growth in the number of individuals with dementia is particularly relevant, since they are exceptionally vulnerable to poor care and least able to assert and protect their own rights.

- **Information About Quality:** Available evidence about the quality of care is troubling. Little systematic information is available about the quality of programs outside nursing homes (e.g., home health care, respite care, adult day care). Long-term care in nursing homes, while improved, still has substantial quality problems.
- **Cost Containment:** The overwhelming preoccupation with cost containment may detract from efforts to improve quality or to assure even a uniformly acceptable minimum level of quality in long-term care services.

Demographics and Patient Debilitation

An important reason for concern about quality is the increasingly debilitated condition of individuals needing long-term care. Within the last decade, people admitted to nursing homes have been older and suffer from more chronic diseases and functional disabilities (174). That trend may escalate because of recent changes in Medicare’s hospital payment policies that tend to encourage earlier discharge of patients (104). In addition, testimony at recent hearings before the U.S. Senate Special Committee on Aging and a survey of agencies by the Aging Health Policy Center suggest that Medicaid’s Prospective Payment System for hospitals has also increased the demand on home health agencies (184,195). Agencies report the greatest increase in demand is among those 75 to 84 years old (195). Limitations on nursing home bed supply may increase the debility of individuals seeking home health and other informal long-term care services. Thus, throughout the system, providers are encountering a demand for more

skilled services in addition to the widespread need for nontechnical care and assistance with activities of daily living.

Troubling Evidence About the Quality of Long-Term Care

Despite the considerable progress that has been made, and the outstanding performance of many providers, quality of care continues to be a concern. Media attention and awareness of nursing home negligence has been more intense than that for other long-term care providers. Likewise, State and Federal studies of the quality of care delivered have focused on nursing homes.

Noninstitutional Long-Term Care. Little systematic evidence is available about the quality of long-term care for such services as home health, home chore, respite, and adult day care. In part, this lack of knowledge is because of the relative paucity of government funding, weak standards of care, and the difficulties of monitoring the performance of these providers. In addition, because of the policy emphasis on the cost containment potential of noninstitutional care, most studies of programs such as home health and adult day care have focused on cost and utilization issues and on the potential of these programs for delaying or preventing nursing home placement (76). Little attention has been directed to the quality of services such agencies provide in general.

Information on the quality of these services for individuals with dementia is even more scarce. The one consistent finding across the few studies done confirms the general impression that home health, home chore, and adult day care agencies typically do not serve individuals with the kinds of cognitive impairment, behavioral problems, and incontinence that are typical of persons with dementia (93,106).

In addition, little is known about the quality of noninstitutional services because of the scarcity of the services themselves (92; see also 73,165). The range and scope of most programs area function of federally sponsored efforts, but relatively little Federal funding is directed to establishing or expanding noninstitutional long-term care services (101,161).

Several studies have found that home health, home chore, and adult day care services increase contentment and satisfaction among those who receive them compared with those who do not (57,194). In addition, there is evidence that home health care can produce measurable improvements in functional status (e.g., 91,123) and some clinical outcomes (28,59). These findings, however, tell more about the potential for desirable outcomes from noninstitutional services than about the actual level and range of quality among the broad spectrum of providers.

observers generally indicate that the quality of services, as well as the scope of what is provided, varies from agency to agency. Studies have found striking inconsistencies among agencies in the types of client needs that are identified and the types of service provided (150,191). One researcher, for example, found substantial disagreement about the type and frequency of home care services needed by a group of 50 individuals assessed by five multidisciplinary teams (physicians, social workers, and nurses) (15 1). Similar studies found little consistency among providers with respect to services actually used by people receiving home care (8,34).

The scarcity of studies focusing on the quality of noninstitutional long-term care and the lack of clear criteria for assessing these services make judgments about their quality difficult. Some evidence, largely anecdotal, suggests widespread disparity of in-home services provided (e.g., 179)183). No comprehensive effort has been made to determine how pervasive the poor quality of care is.

The General Accounting Office (GAO) studied Medicare's home health services (173). The primary focus of that study, like others, was on utilization and substitution of aide services for care previously provided by family and friends. The study also identified factors that adversely affected proper use, and that have implications for the quality of services. GAO found that physicians who authorize home health services do not take an active oversight role in the program. GAO also found that medical documentation in the agencies' client records is often incomplete. These findings indicate the difficulties of effectively monitoring the quality of home care.

The initial lack of systematic, comprehensive information on the quality of noninstitutional long-term care services is also troubling because of the changing ‘(dogma of home care)’ (190). During the early 1970s, it was widely asserted that in-home services were less costly than nursing home care for frail and disabled elderly people. Indeed, while advocates for older Americans asserted that community-based long-term care was preferable to nursing home care, it was the cost containment argument that most attracted policy makers. As time passed and the number of empirical studies focusing on costs grew, the discussion moved toward the position that, while costs could go either way, noninstitutional care was always preferable.

As noted, recent evidence indicates there is reason to believe that expansion of home health, adult day care, and other alternatives is not likely to reduce aggregate nursing home use (193). Moreover, the assertion that in-home services are most cost-effective or preferable is open to question. There is, some observe, a concern that policies to discourage use of nursing homes are creating a ‘(class of isolates)’ (190). For individuals with dementia and their families, this concern is particularly worrisome, since the isolates may include not only the ill person but also the primary caregiver. Given the lack of information and the difficulty of monitoring the quality of services, there is concern that “a substantially unregulated home care industry will outdo the nursing home scandals of the 1970s” (190).

Nursing Homes and Domiciliary Facilities.—Information about the quality of nursing homes and board and care facilities is considerably more extensive and better documented. Preliminary findings of studies at Duke University’s Center for the Study of Aging and Human Development suggest that most families seek and receive in-home or community-based services only immediately before nursing home placement of someone with dementia. Thus, nursing home and domiciliary care are the primary types of formal long-term care most persons with dementia experience (63).

The development of health and safety regulations incorporated in State licensure laws and Federal certification standards for Medicare and Medicaid, combined with increased professionalism

and expertise in the nursing home industry, have contributed to significant improvements in the quality of several aspects of long-term care. Perhaps most dramatic is the improved safety of nursing homes, as regulators concentrated their inspection and enforcement activities on securing facility compliance with building and fire safety codes. Despite such advances, most observers acknowledge that even today the quality of care nursing homes provide varies significantly. The quality of life is superior in a relatively small percentage of homes—perhaps 15 percent nationwide—and seriously substandard in an estimated 20 to 30 percent (79,87,113,133,184).

In 1975, the U.S. Senate Subcommittee on Long-Term Care estimated that at least 50 percent of the Nation’s nursing homes were substandard, with one or more life-threatening conditions (184). Based on a national inspection of nursing homes in 47 States and interviews with 3,458 residents in the mid 1970s, the Department of Health, Education, and Welfare (DHEW) found widespread deficiencies—overdrugging of residents, inadequate medical attention, insufficient diets, and a widespread failure by homes to provide needed therapies. DHEW found, for example, that only 31 percent of the residents needing physical therapy received it, and that 80 percent of medications were improperly administered (180).

Although conditions have improved in many nursing homes, more recent studies by State commissions and independent researchers confirm many of these earlier findings. One of the most common criticisms concerns overmedication with antipsychotic drugs and tranquilizers (86,133,142, 188). Other significant problems in care are noted. In fact, during the last decade State studies have found significant and troubling signs of poor-quality care:

- Virginia, which prides itself on having the best nursing homes in the country, found an average of 23 deficiencies in minimum health and safety standards per home (188).
- Missouri found that 25 percent of its nursing homes failed to meet minimum health standards (122).
- A Texas study revealed that 33 percent of the facilities violated minimum dietary standards (169), and a subsequent task force that visited

113 facilities found that 25 percent had "(inadequate interior maintenance" (cracked or peeling paint, signs of water leaks, broken windows in resident rooms, etc.) and 33 percent had "offensive odors" in residents' rooms (168).

- Ohio found that 25 percent of its nursing homes spent less per resident per day on food than the amount considered by the U.S. Department of Agriculture and a panel of consultant dietitians to be the minimum necessary to meet the essential nutritional needs of an elderly person (133).

Other problems continually cited as problems in nursing home care include overuse of psychotropic drugs, misadministration of medications, excessive use of physical restraints, inadequate medical care, inattention to residents' rights and mental health needs, inadequate or inappropriate food and food service, failure to provide needed therapies, and inattention to care that restores or minimizes functional decline (10, 30, 31, 37, 38, 39, 52, 57, 69, 77, 79, 80, 85, 113, 116) 121, 1, 127) 128, 129, 133, 134, 141, 168, 169, 188). The combination of physical, functional, and cognitive disabilities suffered by individuals with dementia makes them particularly vulnerable to these problems.

Quality problems in formal long-term care services are not limited to nursing homes. Studies and reports about domiciliary care facilities also have been the subject of studies and reports that reveal a number of serious quality problems. Identifying problems in such facilities and remedying them through a systematic quality assurance system, however, is much more complex than with nursing homes. As described in chapter 6, domiciliary care facilities include everything from board and care homes and residential facilities to adult foster care homes and halfway houses. Facilities vary substantially in size, population, services provided, and source and level of payment. No direct Federal regulation of domiciliary care exists, and States vary enormously in the number of facilities they regulate and the extent of the regulatory structure. Given that diversity, the role and purposes of any particular domiciliary care facility are not always clear and cannot be generalized. Thus, establishing quality standards

for their performance is complex. Despite the large numbers of individuals residing in such facilities, relatively little is known about them.

Domiciliary care facilities (DCFs), as described in this chapter, are categorized as board and care homes. These facilities primarily serve an older population and are intended to provide food, shelter, and some degree of protection, supervision, or personal care that is generally nonmedical in nature (29, 95) 112, 143). The "personal care and oversight" responsibilities of board and care operators are established by State regulations, and vary substantially (143). Usually these include assistance with the activities of daily living (ADLs) (e.g., eating, bathing, grooming), assistance in obtaining needed medical and social services, supervision of residents' medications, and help in transportation and shopping (168). Despite State requirements, board and care homes vary in the quality and extent of services and care they provide.

Board and care facilities have received less sustained attention and study than nursing homes, but a series of fatal fires and stories of abuse and neglect during the 1970s focused national attention on their problems. The studies and investigations found widespread and serious safety and quality problems—at the same time State and Federal policies were encouraging the expansion of this sector. States were "deinstitutionalizing" patients from State mental hospitals. State and Federal policies under Medicare and Medicaid were encouraging the reclassification of nursing home residents from higher to lower levels of care, often out of the nursing home altogether.

Extension of the Federal Life Safety Code for intermediate care nursing homes forced many facilities out of Medicaid, and many converted to board and care or boarding homes. States could reduce their financial burden by moving individuals from licensed nursing homes and State hospitals to boarding homes and board and care facilities. The U.S. Senate Special Committee on Aging reported in 1975 that the result was increasing numbers of elderly people being "relegated to facilities which were unsafe and in which poor care, inadequate nutrition, negligence, physical abuse, and unsanitary conditions were rampant" (186).

Despite a series of Federal initiatives, in 1982 the Inspector General of the Department of Health and Human Services reported a continuing low level of State regulation and oversight of board and care facilities (177). Other studies, cited below, echo this finding, supplementing it with a litany of reported abuses and citations of substandard care.

Residents of board and care facilities suffer from a variety of physical, functional, and mental impairments and require substantial assistance and supervision on a regular basis. As described in chapter 6, memory defects and disorientation are common problems among elderly residents of board and care facilities. Evidence suggests that the living conditions, care, and services experienced by many residents is deficient. One common finding is that a majority of elderly people in DCFs are living in large, old, often dilapidated facilities, in mixed residential and business neighborhoods that are decaying. Further, they are doing nothing but watching television, sitting, staring at the walls while waiting for the next meal, or wandering the streets (45,115).

Rehabilitation programs or those designated to prevent avoidable decline in either mental or functional (ADL) capacity are rare, despite high levels of disability (45, 115,137,154). Even where therapeutic and social services are available, comparisons of assessed needs to services received revealed serious deficits in dental, medical) nutritional, and transportation services, as well as in socialization and recreation activities (45,1 15,137). Finally, mental health services are rare relative to need for all but mentally retarded residents.

The findings of these studies have been supported by Federal reports and congressional studies and testimony. The Department of Health and Human Services (DHHS) conducted a study of board and care homes and found an erratic level of personal care and a lack of supportive services for residents (178). Subsequent studies by the U.S. House Select Committee on Aging and GAO revealed evidence of resident abuse, substandard health care, unsanitary conditions, and unsafe facilities (172, 181, 182). As the House Select Committee on Aging reported, its investigations and

hearing testimony revealed “widespread instances of poor living conditions and negligent care” (182).

Cost Containment and Quality of Care

Efforts by policy makers to reduce public expenditures draw additional attention to questions regarding long-term care; increasing pressure at State and Federal levels to contain costs may be problematic from a quality perspective. One Medicaid director describes long-term care as “the black hole of State budgets,” and throughout the Nation, cost containment is the central long-term care issue. As several observers note, there is potential conflict between cost containment and quality (41)71,97).

Empirical research has not directly addressed the relationship between a provider’s costs or reimbursement levels and the quality of long-term care provided. Some studies suggest a weak relationship between cost and quality of care (151). Others, however, report that certain cost containment policies correspond to reduced quality of care (19,20,32,33,71 ,151). The actual relationship between resident’s characteristics (case mix), quality of care, and costs remains difficult to assess.

State reimbursement rates for nursing homes (see table 10-1) and reimbursement methodologies vary widely. Lack of conclusive information regarding the relationship between cost and quality of care, however, makes it difficult to estimate the significance of these differences. Many argue that strong quality assurance mechanisms are essential to compensate for discrepancies in reimbursement levels provided by different States (79,151).

Similar arguments are made with respect to domiciliary care. The drive for cost containment in State nursing homes and mental health facilities often results in shifting individuals with relatively significant dependencies and care needs out of intermediate care facilities and State mental hospitals into less well-monitored board and care facilities (65,163). Several studies suggest that the current reimbursement method for board and care housing is inadequate to encourage the upgrading of DCFs to meet even the existing minimal safety and quality of care standards (163,164,

Table 10-1.— Nursing Home Per Diem Reimbursement Rates, By State, 1978-83

State	SNF ^a reimbursement rates (rate in dollars)						ICF ^b reimbursement rates (rate in dollars)
	1978	1979	1980	1981	1982	1983	1982
Alabama	—	114.93	114.13	107.35	105.27	119.31	104.26
Alaska	22.85	26.95	29.33	30.79	33.38	37.61	25.81
Arizona	—	—	—	—	—	—	—
Arkansas	—	20.97	23.35	25.53	27.39	—	25.35
California	—	30.81	31.65	36.35	37.36	38.09	28.90 ^c
Colorado	—	23.14	26.03	28.24	30.78	—	30.92
Connecticut	26.16	30.17	33.22	36.50	41.60	46.78	26.57 ^c
Delaware	30.40	35.68	36.96	41.59	44.49	29.59	44.28 ^c
District of Columbia	—	52.38	66.93	65.90	—	—	50.87 ^c
Florida	—	18.79	21.13	23.82	26.01	—	33.21
Georgia	—	23.38	25.93	28.63	34.32	25.94	—
Hawaii	—	55.05	62.11	71.56	79.45	—	58.18 ^c
Idaho	21.93	22.00	21.19	25.35	27.61	28.72	31.33
Illinois	22.14	24.93	27.40	28.61	30.24	30.76	34.04
Indiana	—	—	34.90	38.27	42.32	45.86	32.68
Iowa	28.75	29.75	33.56	44.62	59.51	73.55	25.89
Kansas	20.14	23.83	25.48	27.80	31.75	32.44	22.16 ^c
Kentucky	—	37.50	45.00	45.00	51.31	49.35	31.95
Louisiana	23.58	23.58	26.73	31.85	29.65	34.80	26.62 ^c
Maine	—	54.98	56.20	61.15	65.93	71.20	40.30
Maryland	26.21	29.30	31.52	36.14	39.53	—	36.14 ^c
Massachusetts	—	32.71	39.57	41.06	44.40	—	33.24
Michigan	—	29.20	31.50	35.56	36.72	38.98	36.72
Minnesota	29.50	32.07	38.25	44.81	47.36	51.32	35.88 ^c
Mississippi	—	—	28.59	31.43	34.09	36.22	32.53
Missouri	15.55	18.37	26.80	30.00	35.00	40.00	29.12
Montana	—	30.20	33.85	36.75	39.58	—	36.75 ^c
Nebraska	—	—	—	41.23	44.64	49.27	26.07
Nevada	—	30.15	37.72	40.25	47.50	47.50	43.61
New Hampshire	—	27.13	29.84	36.26	44.88	59.22	44.54
New Jersey	36.26	38.73	41.83	46.13	51.91	58.05	43.81
New Mexico	—	58.93	—	60.86	73.41	82.10	32.08
New York	49.65	55.35	62.17	67.63	73.98	78.70	49.21
North Carolina	34.19	36.58	41.78	45.56	48.98	52.03	33.49
North Dakota	—	26.44	31.91	37.87	43.40	45.02	30.00
Ohio	—	—	—	35.39	38.22	39.39	36.80
Oklahoma	—	21.00	26.00	29.00	32.00	32.00	26.53
Oregon	24.82	28.61	34.23	39.79	45.15	50.12	32.85
Pennsylvania	25.50	25.50	32.47	33.15	—	—	37.62
Rhode Island	29.75	36.43	40.86	47.33	49.23	53.71	38.95
South Carolina	—	35.29	39.84	44.25	40.77	40.77	32.05
South Dakota	19.10	20.94	23.33	26.36	30.08	33.39	26.88
Tennessee	32.80	32.50	36.20	40.50	42.60	46.36	27.40 ^c
Texas	24.74	28.07	30.86	33.66	35.67	38.25	26.79
Utah	—	32.30	36.52	39.32	42.26	44.96	34.06 ^c
Vermont	28.86	31.49	34.84	39.25	44.07	—	44.07
Virginia	—	42.54	46.43	51.26	61.90	—	42.66
Washington	—	23.33	28.92	31.68	35.25	35.92	34.37 ^c
West Virginia	28.11	30.57	32.89	36.15	41.21	44.38	37.46
Wisconsin	31.85	35.00	38.00	42.00	42.52	44.22	32.00 ^c
Wyoming	23.13	26.30	29.90	33.71	38.12	40.85	33.71 ^c

^aSNF—skilled nursing facility.^bICF—intermediate care facility.^cData for 1981.

SOURCES: SNF data for 1978, 1982, and 1983 from telephone interviews with State Medicaid agencies conducted by the Aging and Health Policy Center (AHPC); SNF data for 1979, 1980, and 1981 from AHPC and LaJolla Associates; ICF data for 1982 from LaJolla Associates.

172,180). At the same time, budgetary pressures make it difficult for States to increase payments to DCFs—or to increase funds allocated to monitoring the adequacy of services. Much the same can be argued about payment levels and resources for monitoring quality in other in-home and community-based long-term care services. A study by the Aging and Health Policy Center indicates that home health agencies are experiencing or anticipating a decrease in Medicaid reimbursement (195), and that funds for monitoring performance and assuring quality are scarce.

Inadequacy of the Current Regulatory System

Given the documented problems in long-term care quality, particularly in nursing homes and DCFs, and the concern about the adequacy of in-home and other long-term care services, the obvious question is whether the current regulatory structure is adequate to remedy problems in quality.

Historical Perspective

Despite 20 years of Federal regulation, the problem of quality in long-term care has been addressed incompletely and only episodically, for several reasons. At the outset, policy makers' most immediate concern was securing widespread participation by health care providers in Medicare and, to a lesser extent, Medicaid (50). They feared that imposing strict quality of care standards on health care institutions would severely restrict program beneficiaries' access to health care. Although nearly 6,000 facilities applied to participate in Medicare by December 1966, only 740 were able to achieve compliance by July 1967 (187).

As a result, at both Federal and State levels, policymakers chose not to demand full compliance with the health and safety standards established for hospitals and nursing homes participating in Medicare and Medicaid. Instead, institutions that were in "substantial" compliance were allowed to participate and receive reimbursement only if they had acceptable plans to correct deficiencies. That approach persists today. Few nursing homes, for instance, are in full compliance with Federal

health and safety standards. Many continue to operate with waivers of some standards and with plans to come into compliance for others.

The historical context for government regulation of health care also helps to explain the absence of policy focus on quality. Government-mandated health and safety standards originated in programs providing funds to institutions caring for children (67). These regulations were as much a product of concern that government receive good value for its money as they were of worry about the quality of life and care for the institutions' residents. The evolution of nursing home standards at the Federal level followed much the same pattern, emerging in conjunction with Medicare and Medicaid funding. The result was the promulgation of health and safety standards that sought less to define and assure high quality of care and life for nursing home patients than to ensure that government funds were not expended for obviously substandard care.

The Federal role in assuring long-term care quality thus has three components: 1) the formulation and promulgation of health and safety regulations; 2) the inspection of providers to determine the level of compliance with regulations; and 3) the enforcement of regulatory standards and administration of sanctions for noncompliance. The effectiveness of each of these components—regulatory standards, monitoring, and enforcement—is the subject of continuing debate.

The Regulatory System for Nursing Homes

States promulgate health and safety standards that nursing homes must meet in order to receive an operating license. Any home that wishes to participate in Medicare or Medicaid must meet additional Federal and State standards (i.e., "conditions of participation" for skilled nursing facilities and "standards of care" for intermediate care facilities). Once certified as being "in substantial compliance" with these standards, a nursing home qualifies for reimbursement by Medicare or Medicaid for the care provided to program beneficiaries. More than 80 percent of all nursing homes participate in one or both programs. Medicaid assists in paying for the care of at least 70 percent of all nurs-

ing home residents, and over 80 percent of those in homes in some States (82).

The following are some of the more common criticisms of the regulatory system, as it applies to nursing homes:

- **Minimums Become Status Quo:** The standards themselves have been acknowledged to represent “minimums”) and many critics argue that these minimums, particularly in staffing and mental health support, are too low to assure acceptable quality of care. That may be particularly problematic for persons with dementia, who require substantial assistance and supervision.
- **Structural Characteristics Emphasized:** Regulations focus almost exclusively on structural characteristics and “inputs” that facilities must provide (e.g., door widths, square feet of room per resident, and staff/resident ratios). The assumption underlying the specification of these inputs is that they are associated with the provision of at least minimally acceptable care. In effect, the Federal regulations and survey forms measure the capacity of a facility to provide certain kinds of inputs and infer that the outcome will be acceptable care (180). State reports have been critical of that focus in Federal standards. While the necessity of structural and input standards is not questioned, most States argue for an enhanced focus on actual facility performance and resident outcomes (37,7 i’, 128,129)133).
- **Ambiguous Terminology** State reports also criticize Federal regulations for a lack of clarity on certain key elements in the standards. For instance, the lack of clear guidelines about what constitutes “imminent danger” or “adequate” staffing to meet the needs of residents places a substantial burden on surveyor judgment. It also makes enforcement more difficult, since such individual judgments are less likely to be accepted in court (31,37,77,129, 133)188).
- **Medical Model of Care Emphasized:** The regulations are widely criticized for being largely a product of a medical model of long-term care. Although nursing home residents need expert medical care and benefit from

restorative or rehabilitative therapies, current regulatory standards tend to ignore many other important aspects of long-term care. As the New York Moreland Act Commission argued, existing regulations do not capture many of the essential requirements of nursing homes as **homes (128)**. Others note that the social and psychological needs of residents are inadequately addressed by regulations. These concerns are particularly important given the extent of mental and cognitive impairment among nursing home residents.

Inspections.—While the responsibility for enacting laws and promulgating standards is clearly divided between the States (for licensure) and the Federal Government (for certification to participate in Medicare and Medicaid), the relationship with respect to inspections is somewhat more complex. Licensure inspections are solely the responsibility of the States, most commonly the State department of health or its equivalent. Inspection of homes participating in Medicare is the responsibility of the Federal Government, which contracts with State agencies for these surveys. Under Medicaid, inspection and certification responsibility rests with the State department handling public assistance programs. Usually that agency subcontracts with the State facility licensing agency to perform the Federal surveys. Alternatively, the public assistance agency may perform the surveys with one of its own divisions, subject to Federal approval.

For both Medicare and Medicaid, the Federal Government has “look behind” authority. That is, Federal surveyors may conduct independent inspections of certified nursing homes to audit or validate the States’ certification activities, and the Federal Government can decertify substandard facilities directly. The Federal certification survey process is intended to measure provider performance and identify deficiencies that result in poor quality care. It is also meant to produce sufficient documentation of deficiencies to support the Government case in contested enforcement actions.

Both State and Federal inspections have been criticized on two major points:

1. **Primary Focus on Records:** Studies find nursing home records are often incomplete

Box 10-A.—Judicial Review of Nursing Home Inspection Process

The original suit, *Smith v. O'Halloran* (159), was filed on behalf of a group of nursing home residents in a Denver, CO, facility. The suit alleged poor care and violations of residents' rights, but more importantly it charged the Federal Government with failing to adequately monitor the performance of providers. During the trial, residents proved a variety of violations of Federal regulatory standards, including theft of personal funds, overuse of psychotropic drugs, inadequate care resulting in bedsores, inadequate skin and nail care, inadequate bowel assistance, and unsanitary conditions.

The case against the government agencies was based on the theory that Title XIX of the Social Security Act requires a Federal nursing home survey process that determines whether residents are actually receiving care they need, not merely whether facilities have the potential or capacity to provide needed care. In 1978, the Colorado Health and Medicaid agencies joined the plaintiffs, arguing that the mandatory Federal survey process was inadequate to determine whether residents receive needed care.

A Federal district court found that: 1) serious deficiencies exist in some nursing homes; 2) the current survey system is facility-oriented rather than resident-oriented; and 3) it is feasible for DHHS to develop a survey system focusing on resident needs and care delivery. The court held, however, that DHHS had no legal obligation to develop such a resident-focused survey system.

In *Smith v. Heckler*, the Federal Tenth Circuit Court of Appeals reversed the lower court's decision, holding that the Medicaid law does impose a duty upon the Secretary of DHHS "to establish a system to adequately inform herself as to whether the facilities receiving Federal money are satisfying the requirements of the Act, including providing high quality patient care."

The appeals court returned the case to the district court to determine what survey system would satisfy the Secretary's duty. The Health Care Financing Administration indicated to the court that it would implement a resident-oriented survey system in August 1988. The court is holding hearings to determine whether HCFA's proposed changes in the survey system, known as the Patient Care and Services (PaCS) survey, will meet the appeals court standard.

and tend not to reflect actual care and conditions (58,87,102,119). Thus, surveys generally measure only the homes "paper compliance" with input and structural standards—not the care actually provided or the impact on residents' well-being (77,127,128,134,180). Of several hundred items on current Federal survey forms, for example, fewer than 20 require surveyors to actually observe residents. A New Jersey report on nursing home quality argues that this can contribute to poor care:

If the surveyors simply rely on written documentation . . . and do not physically check the patients, many problems, such as bedsores, poor circulation, dehydration, etc., may remain uncorrected and undiscovered (127).

2. predictable Timing of Surveys: Survey agencies routinely notify facilities in advance of annual certification inspections. Even without formal notification, the regular schedul-

ing of annual inspections may give facilities sufficient warning of when to expect a visit. That aspect of the survey process is criticized for yielding inaccurate evaluations. Several States note that facilities correct deficiencies only immediately prior to expected surveys (10,31,37,116,121,128,134).

The Health Care Financing Administration (HCFA) has tested a resident-focused quality assurance survey system, Patient Care and Services (PaCS), in three States—Connecticut, Rhode Island, and Tennessee—and in select facilities nationwide. The system was to be fully implemented in each State by August 1986. PaCS aims to redirect the survey process from emphasizing facility structure and theoretical caregiving capacity toward evaluating actual delivery of care and its outcomes. PaCS requires surveyors to directly observe and document specific aspects of the physical environment, specific care procedures, and a repre-

sentative sample of residents. Several features of the system require further development (e.g., a formal protocol for sampling of residents and for evaluating the proportion of undesirable outcomes attributable to care provided). However, the focus on outcomes of care rather than facility structure and written records of care has been commended as a potentially promising way to improve quality assurance (79).

Additional weaknesses of the survey process include inadequate staffing, training of survey staff, and inconsistencies between surveyors. During the last decade, some 15 State studies of nursing homes and the regulatory process have been conducted. Six reported inadequate resources for survey staff to be a significant problem (Arkansas, California, Colorado, Illinois, New Jersey, and Ohio); seven State commissions argued that survey staff training was inadequate (Arkansas, California, Colorado, Illinois, Michigan, New Jersey, and New York). Several studies argued that inadequate resources directed to the critical task of monitoring facility performance result in disparities in the performance of surveyors and inconsistencies in the numbers and types of deficiencies cited from State to State.

One analysis of data on Federal certification deficiencies found that the proportion of a State's skilled nursing facilities having more than 25 deficiencies in 1981 varied from none in Delaware to 100 percent in the District of Columbia (176). Another study found substantial variation from State to State in the most frequent types of deficiencies cited (166). Although such variations may in part reflect genuine differences in facility performance between States, they are also, to some degree, the result of unacceptable differences between States in the focus and accuracy of surveys (79).

Weaknesses in the survey process have been the focus of a protracted legal battle (see box 10-A), settled by the 1984 decision of the 10th Circuit Court of Appeals (158). The court's decision requires the Federal Government to modify the Federal certification survey process so as to assure quality of care in nursing homes more effectively.

Enforcement.—Even if the Federal standards were improved and the revised survey process complies with the decision in *Smith v. Heckler*, inadequate enforcement of standards could remain an impediment to improving quality of care.

Federal procedures for dealing with nursing homes found to be out of compliance are oriented toward helping them improve rather than toward enforcing certification standards. Current policies permit States to certify facilities in "substantial compliance" or those with "plans of correction." Policies encourage States to consult with and "persuade" facilities to come into compliance, rather than to punish them. In fact, under Federal regulations, State agencies cannot punish a violation immediately. Survey agencies must issue a notice to the operator of a substandard nursing home, giving the facility time (usually 30 to 60 days) in which to correct deficiencies. The HCFA Provider Certification State Operations Manual specifically instructs the survey agency to try to resolve cases before they are referred to the formal administrative enforcement agency for sanctions for non-compliance.

That posture may appear both reasonable and beneficial in some cases, but its overall effect is to allow States to continue certifying facilities that provide poor or marginal care. Studies find large numbers of "in-and-out" facilities: marginal or substandard long-term care facilities that are chronically out of compliance when surveyed temporarily eliminate deficiencies under a plan of correction, then quickly lapse into noncompliance until the next inspection, often a year later (31,77, 79,128,134). In other cases, nursing homes may be decertified (see next section) but quickly correct deficiencies to be promptly recertified for Medicare or Medicaid participation (4).

Even when State licensure and certification agencies and HCFA regional offices proceed with recertification, facilities still re-enter the program relatively easily. Federal Medicare regulations call for "reasonable assurance" that deficiencies that led to termination will not recur (42 CFR 489.57). In practice, however, State agencies feel they have no authority to deny certification to a facility that is in substantial compliance with Federal standards—whatever its prior record (4,124).

Recertification.—Termination of a provider's contract to participate in Medicaid or Medicare is the primary Federal method for securing compliance or punishing noncompliance. Representatives of consumers, providers, and regulators consistently criticize recertification as an enforcement tool; the absence of intermediate enforcement mechanisms is seen as a problem. Consumers and regulators advocate the introduction and implementation of a broader range of sanctions. During the last decade, nine State reports have argued that although recertification is the only authorized sanction, it is ineffective and rarely used (Arkansas, Colorado, Illinois, Minnesota, New Jersey, New York, Ohio, Texas, and Virginia) (also see refs. 6,29).

Concentrating enforcement on a mechanism that, if imposed, generally means closing a facility, is regarded by many as excessively severe and counterproductive. Recertification, particularly for minor deficiencies, may appear inappropriately harsh, and therefore not be used. As a result, providers may have little incentive to correct deficiencies.

Recertification is also criticized for the burden it imposes on residents and on State agencies to find placement for residents removed from substandard facilities. In addition to problems of bed scarcity, transferring individuals needing long-term care to a new facility maybe traumatic, particularly for those with dementia, and can be harmful to their health (138). Thus, even in States where beds are available (e.g., Texas), decertification may appear an undesirable, if not unworkable, sanction (79,124).

Other problems with recertification as an enforcement mechanism are the cost and time involved in the legal proceedings associated with closing facilities or terminating provider contracts. Courts have held that a license to operate a nursing home and, in some cases, the contract to participate in Medicaid, are property rights. Thus, homes can challenge these sanctions, first in administrative hearings and then through a series of court appeals. That process is costly for State regulatory agencies. The facilities, however, can report the proceedings as an expense of doing business and be reimbursed through Medicaid or

Medicare (134). The process often results in years of delay before sanctions are imposed (10,37,52, 127)129)133), Agencies typically drop all action if a facility comes into compliance at any time during the appeals process (134). The result is that nursing homes often receive no penalty for even the most severe violations of Federal health and safety standards.

Two intermediate Federal sanctions could be used in place of recertification. The issuance of time-limited provider contracts, pending correction of deficiencies, is available for certification violations. Second, the omnibus Budget Reconciliation Act of 1981 (Public Law 97-35) authorized an intermediate Federal sanction: suspension of Medicare payments for patients admitted to facilities not in compliance with Federal conditions of participation but in which the deficiencies do not pose imminent threat to patients' health. Similar authority was granted to the States for Medicaid-only facilities. DHHS published the proposed regulations for this sanction in the Federal Register, July 3, 1986. The regulation became effective August 4, 1986 (51 FR 24484).

The inappropriateness of recertification and the failure of the Secretary to implement the intermediate sanction authorized by Congress 6 years ago have contributed to continued reliance by State regulatory agencies on attempts *to persuade* providers to come into compliance with Federal standards. Faced with an unworkable sanction, the dominant model of enforcement activity resorted to by States is "consultation" with facilities that fail to meet Federal certification standards. For instance, surveyors may choose not to record deficiencies, attempting to use this discretion to persuade facilities to correct the failure in a "reasonable" period of time. Even in cases where deficiencies are reported on a Federal survey report, State agencies still attempt to use education and consultation to achieve facility compliance with minimum Federal health and safety standards.

Most State studies are critical of the "consultation" model, arguing that it often results in inaccurate survey reports and fails to assure uniform and continual compliance with Federal regulations. In particular, it fails to address the problem of facilities that are habitually substandard, com-

ing into compliance only to prevent recertification but reverting to noncompliance as soon as the threat is removed for another year.

Thus, although States are given the responsibility of enforcing Federal standards, they lack meaningful and workable Federal sanctions. That failing is a constant source of discontent and of criticism from the States (6,29,30,77,128,134,169).

Regulation of Board and Care Facilities

The regulatory structure for board and care facilities has been characterized as more fragmented and weaker than that for nursing homes. In general, Congress has maintained that it has little financial leverage over such facilities and, thus, little authority to demand Federal health and safety standards. Congressional actions aimed at improving board and care facility quality have been largely indirect.

The 1976 Keys amendment to the Social Security Act was the first attempt to exert some Federal pressure. The amendment gives States complete regulatory authority over DCFs, requiring them "to establish, maintain and insure the enforcement of standards" concerning admission policies, life safety, sanitation, and civil rights protection in facilities where three or more recipients of Supplemental Security Income (SSI) reside.

Three weaknesses have been identified in this Federal initiative:

1. Although the legislation encourages many States to clarify the language in their standards and regulations, State regulations largely exclude specifications about residents' personal care and social needs (45,14,142,162,163).
2. The amendment is worded so that it applies only to board and care facilities that provide some form of medical or remedial care. That language has been interpreted as covering board and care homes that provide protective oversight or supervision, but not those that provide only food and shelter. That distinction dramatically narrows the universe of facilities covered by the Keys amendment, excluding an estimated 300,000 boarding homes in which large numbers of SSI recipients may reside (137,162,177).
3. The "penalty provision" of the Keys amendment has been widely criticized as inappropriate and unworkable (177). Under Keys, the Federal Government is authorized to reduce a recipient's Federal SSI payment by the amount of any State supplement "for medical or remedial care" if the recipient resides in a facility not approved by the State as meeting State domiciliary care standards. The intent is to provide an incentive for SSI recipients to move out of substandard or unlicensed facilities into ones that meet State standards. In theory that should force owners of substandard facilities to upgrade their facilities to meet State standards, but in practice it ignores the fact that many SSI recipients lack the physical or mental capacity to find alternative housing—even if it were available. Further, the penalty is taken directly against recipients rather than against substandard facilities or noncomplying States. The DHHS Inspector General has noted that this is "a position which has few—if any—defenders" (177). For these reasons, the "penalty provision" has never been invoked.

Subsequent Federal initiatives have been similarly unsuccessful in assuring improved quality in domiciliary care facilities. The 1978 Amendments to the Older Americans Act (OAA) encouraged nursing home ombudsman programs to include advocacy for board and care residents. Under that voluntary provision, few States expanded the scope of their ombudsman programs (170). The 1981 Rinaldo amendment to OAA, therefore, required State nursing home ombudsmen programs to investigate complaints about board and care homes. However, as several directors of ombudsman programs observe, without a substantial increase in State or Federal funding, they have insufficient staff to implement this provision effectively (53,72,146).

As a result of findings about inadequate quality and the weakness of existing regulatory structures, DHHS developed recommendations and a strategy to remedy what it felt were significant problems in board and care homes (180). The strategy includes an attempt to develop model State statutes, a grant to the National Bureau of Standards to develop fire safety standards, establishment of a central unit within DHHS to monitor

board and care issues, and partial withholding of OAA funds from States that fail to certify that they maintain and enforce safety and quality of care standards as part of their OAA plan. No additional Federal funds have been made available to the States, however, to improve standards, monitoring, or enforcement of existing regulations; nor have any penalties been imposed on States for failure to uphold quality of care standards. Thus, the burden of improving quality of care and life in board and care homes continues to rest entirely on the States, whose efforts in that regard have been limited, despite their relatively long history of regulating board and care facilities.

States have made little progress in developing uniform and comprehensive standards of care or in developing an effective monitoring and enforcement system. Although each State has some regulations for licensing or certifying board and care facilities, significant variations exist in these regulations and in the level of effort States invest in inspecting facilities and enforcing standards of care and safety (5,64,164).

Variation in State regulatory policies reflect variations in the types of facilities defined as domiciliary care facilities. Programs and facilities specifically for mentally retarded adults tend to be the most formally and strictly regulated. Board and care facilities housing an elderly or mixed adult population have traditionally been subject to only minimal standards and surveillance. A survey of 31 States' board and care regulations noted that regulations focusing on board and care for elderly residents emphasize maintenance (food and shelter) and '(bricks and mortar, " rather than rehabilitation or other therapeutic services (45,154).

Given the characteristics and care needs of board and care residents, State regulatory standards may be insufficient to guarantee quality care. A comprehensive review of board and care standards identified the types of regulations that are the most common nationwide (143):

- **Structural Requirements:** The majority of regulations address structural (e.g., physical plant) rather than procedural (e.g., care) requirements. Given the level of functional and

mental impairment among DCF residents, these standards may be insufficient.

- **Staffing Requirements:** Staffing patterns and staff training requirements are another source of concern. Seventy percent of States that regulate board and care require that a responsible person be present in the facility at all times; but specific staffing standards, including staff/resident ratios, are stipulated in only 28 percent of State regulations. One-quarter of the regulations require some form of training for all staff, and another 27 percent mandate training for only some positions. Half the regulations do not require any staff training,
- **Procedural Requirements:** Regulations regarding actual provision of care were also sparse. Only half the States require board and care facilities to develop individual treatment plans and needs assessment for residents. Fewer than half oblige the operator to ensure that residents have periodic visits or examinations by physicians or nurses. And fewer than half mandate that facilities maintain relations with social service, welfare, or mental health agencies on behalf of residents. One-fourth of the States have regulations requiring that facility operators assist residents in obtaining dental care; one-tenth, eye care; and one-third, mental health services,
- **Residents' Rights:** The issue of resident's rights has been recognized as a pervasive problem in board and care facilities and, by its absence, in regulatory standards. Only a little more than half the States specify that residents have the right to privacy or visitation rights. Only half require facility operators to be accountable for residents' funds. (GAO found that operators frequently abuse residents rights by taking complete control of SSI checks and refusing to give residents private spending money (172).) Complaint and grievance procedures for residents are specified in only 37 percent of the regulations, and nearly all regulations have only minimal standards referring to the removal, relocation, or discharge of residents.

Monitoring Compliance.—Under the Keys amendment, States have sole responsibility for setting standards and inspecting DCFs. Within States,

that responsibility is variously assigned, often to State health departments or mental health agencies. Thus, inspection is even more decentralized, and problems of fragmentation and poor coordination between agencies within States are frequently cited as major problems (163). Further, as previously described, State agencies say inadequate numbers and training of surveyors are major impediments to effective inspection. In addition, inspections of board and care facilities appear to focus almost exclusively on physical characteristics, fire safety, and other structural features rather than on the quality of care provided.

A 1982 survey by the Aging and Health Policy Center (AHPC) describes factors cited by State agencies as barriers to effective quality assurance in board and care facilities (164). Seventy-five percent of the regulatory agencies surveyed reported inadequate funds or personnel to license, inspect, and enforce board and care regulations. Some commentators suggest that understaffing of regulatory programs has been prevalent for some time (147). An investigation of board and care regulations in New York and New Jersey noted that staff shortages hamper surveillance and enforcement of licensed facilities and identification of unlicensed ones (137,162,167). Studies suggest, however, that even if agencies were adequately staffed, inspectors are generally poorly trained and ill prepared to evaluate the quality of care in DCFs or nursing homes (147,164). Further, fewer than one-fourth of State regulations provided for inspection of board and care facilities without prior notice to the operator.

Enforcement. -Enforcement of board and care standards is also lax. Although 87 percent of State regulations require facility operators to correct violations of the standards (143), imposition of sanctions for such violations is rare (147). While States often have the authority to issue a fine, revoke the operator's license, or remove residents, few agencies have used these powers. In the AHPC survey, State agencies argued that the absence of intermediate sanctions, such as civil penalties and fines that are not subject to lengthy administrative or judicial review, impedes their enforcement capabilities and explains the lack of enforcement activity (5,164).

Perhaps the greatest impediment to improved quality assurance activities by the States, however, is the fear that imposing and enforcing more stringent regulations would drive many board and care facilities out of business (137,163). When Michigan began licensing board and care facilities and imposing higher standards of care and safety, for instance, an estimated one-fourth of the facilities dropped out of the program. Ombudsmen in that State suggest that many facilities continued to house the same residents (with the same personal care and oversight needs), but simply converted to "boarding homes," unlicensed and unregulated (16).

Although the burden for assuring acceptable safety and care in board and care homes rests with States, they have few incentives to undertake this task, particularly given the lack of Federal initiatives and funds to match Federal mandates to improve the quality of care in and regulation of domiciliary care facilities. Facing pressure to curtail their Medicaid expenditures on nursing homes and anxious to reduce State-only expenditures on patients in State hospitals, for example, States may have a strong incentive not to impose higher standards on board and care facilities that house people who might otherwise be in costlier facilities.

Regulation of Noninstitutional Long-Term Care Services

As discussed earlier, Medicaid and Medicare were intended to contain the costs of hospital and nursing home services. That concern is apparent in the content of regulations, particularly for Medicare. Reflecting that intention, the Federal definition of services was narrowly circumscribed and medically oriented. Under Medicare, home health services are reimbursable only if they are skilled care services; health-related social support services for chronically ill individuals were excluded from coverage unless the person required some form of skilled care at the same time. Eligibility requires that a Medicare beneficiary be confined to his or her residence, be under a physician's care, and need skilled nursing care or physical or speech therapy. These restrictions, aimed primarily at containing costs, are reflected in the Medicare certification standards.

Home Health Agencies.—In order for a home health agency to provide services that are reimbursable by Medicare, the agency must be certified as being in compliance with Federal standards. Of the more than 12,000 home health agencies, some 6,000 are Medicare-certified (56,75). Federal “conditions of participation” mandate that each agency provide both skilled nursing care and at least one other service from among physical therapy, speech therapy, occupational therapy, medical social services, and home health aide services. The agency may contract with other providers for services it does not directly provide. Other Federal certification conditions relate primarily to operating policies, administrative structure and budgeting, clinical recordkeeping, staffing, and, where applicable, State licensure requirements (183).

The Medicaid program also pays for certain home health services. States have wide latitude in establishing eligibility criteria for individuals and reimbursable services, for establishing reimbursement rates, and for defining standards Medicaid-certified agencies must meet.

The conditions a provider must meet to participate in the Medicaid program are generally less extensive than those for Medicare-certified agencies (7). Under Title XIX, the State Medicaid agency determines whether a home health agency can be a contractor or vendor under the Medicaid program. In general, Medicaid agencies contract only with providers certified to participate in Medicare, in effect piggybacking on the Federal standards and survey process. States that do not have sufficient numbers of Medicare-certified agencies to meet the demand for Medicaid home health services may contract with agencies that meet only State licensing law. Nineteen States, however, have no home health agency licensure requirements (7,56). In these cases, the State Medicaid agency may simply let the contract to the lowest bidder who provides the desired services (7).

In addition to Medicare and Medicaid, the Federal Government has provided funds through the Social Services Block Grant and title 111 of the Older Americans Act. Like Medicaid, these programs generally contract with Medicare-certified home health agencies for the provision of home health services or, where insufficient numbers of

Medicare-certified providers are available, rely on State licensing for quality assurance.

Thirty-three States and the District of Columbia have licensure laws pertaining to home health agencies. Licensure is a tool that allows States to specify quality standards, and is viewed as particularly important for regulating those agencies that provide services only to self-paying clients. For approximately 6,000 non-Medicare certified agencies (and industry experts estimate the number is actually larger), the only requirements they must meet are those imposed by the States. In the States without licensure laws, such agencies are virtually unregulated (7).

Among States that regulate licensure of home health agencies, substantial variation can be found in the content and specificity of the laws.

- Some States have essentially “(pro forma” licensing laws that merely define what constitutes a home health agency and the administrative structure required for the agency to qualify as a home health provider.
- Other States have laws that incorporate service standards, often modeled on Medicare’s, but in some cases more detailed and explicit about staffing, training, services to be provided, assessment of recipient of care, care planning, recordkeeping, and coordination with other agencies.
- In most States, the standards focus largely on the agency’s presumed capacity to provide appropriate services.

Perhaps the most significant deficit in the current regulatory system for home health providers is the absence in nearly half the States of any regulatory quality assurance system for non-Medicare certified home health agencies. Non-Medicare agencies in those States are subject to no required standards and to no monitoring of their performance—even of their capacity to provide acceptable services. Members of industry trade associations note that these agencies have few incentives to engage in a costly quality assurance system on their own, and they are concerned that such agencies may provide unacceptable quality of care. The associations further observe that such agencies tend to have lower charges, since they are not

required to be certified, licensed, or to have internal quality assurance reviews. Because Medicare generally does not cover the kinds of home health services persons with dementing disorders may routinely require, these individuals are at particular risk; if seeking lower cost services, they may turn to unregulated home health agencies.

Like nursing homes, home health agencies receiving Federal reimbursement are inspected at least yearly to determine their compliance with the program's conditions of participation. In States that require licensure for home health agencies, inspections are generally done by the State licensing agency. Alternatively, the State health department, under contract to DHHS, may conduct the inspections. HCFA has the authority to conduct validation surveys to measure the accuracy of the State agency surveys. The impression of home health trade association officials is that these surveys have recently become more detailed, including occasional visits to the agencies (56).

As with regulations for nursing homes, home health regulations represent a structural and resource input approach to standard setting, in which the primary focus is limited to the agency's capacity to provide appropriate services based on its administrative organization and staffing patterns, rather than its actual provision of care. Inspections, too, focus on agency documents and client records, including reports of the agency's internal evaluation of its performance. Thus, the survey process, like that for long-term care in nursing homes, is able to measure only the agency's paper compliance with structural and resource input standards.

Other Services.—Regulatory standards to assure high-quality care are even sparser for other types of long-term care (e.g., adult day care and respite care). Thirty-nine States have established licensing laws for adult day care programs, but the regulations range from specifying only standards for receiving public funding to specifying staffing and services requirements. Home chore services and respite care programs, whether at a facility or in homes, are largely unregulated by local, State, or Federal agencies. In general, only those programs that provide services under Medicaid waivers are subject to any regulation or per-

formance monitoring (141). Thus, relatively little is known about the quality of these programs, and existing licensing bodies do little to assure quality of care. As with home health care, perhaps the greatest potential for identifying appropriate standards and monitoring systems rests with the Medicaid waiver programs and peer review systems.

Among peer review and trade associations, substantial work is being done to develop quality-of-care and service standards. Further, particularly for individuals with dementia and their families, the experience of some States with Medicaid waivers for community-based services provides the greatest potential for developing both voluntary and regulatory quality assurance programs. (These are discussed at greater length later in this chapter.)

Lack of Coordination.—One significant quality problem is that home health and other related home- and community-based services for elderly Americans are not being effectively coordinated, and regulation tends to exacerbate the problem rather than resolve it. For each program, State, Federal, and usually local administration is different; eligibility is different; reimbursement is different; and the programs are targeted at different subgroups. Such targeting often occurs with little regard for the reality of the multiple and complex disabilities and care needs of the chronically ill older population. Medicare is aimed at the "highly skilled care patient," Medicaid at the indigent patient, and social service programs at the relatively well older person. There are at least three problems with this kind of targeting:

1. It ignores the fundamental reality that, for the chronically ill older person, health care and social support needs not only overlap but often compound one another.
2. Classification tends to become arbitrary. The needs of an elderly person may be perceived as social or medical based largely on the program for which the client is eligible or for which the person applies,
3. There is a tendency for the older person to receive only those services that a particular agency directly provides.

Although government regulations and voluntary standards set by agencies both often emphasize

requirements for multidimensional needs assessment, care planning, and service coordination, the reality seldom matches the requirement. Services are rarely provided or even accessible through a single entry point, and, except for special demonstration projects, the formal requirements of interagency arrangements have not proved uniformly effective in coordinating services to older

persons. While requirements may exist and be fulfilled on paper, they are not enforced in practice (171,179). Effective case management and agency coordination are still not widespread, and frail elderly individuals and their families are left to wander through a bureaucratic maze in search of needed and ostensibly available services.

POSSIBILITIES FOR REFORM

Defining, measuring, and assuring quality continue to be vexing problems throughout the field of human services. Formal licensing, certification, and accreditation procedures, although useful in assuring minimum capability among service providers, do not address actual performance or ensure that client well-being is effectively protected. Most standards used to evaluate provider performance represent minimal compliance thresholds. They generally focus on provider capacity and are relatively static, changing little with regard to the state of the art in service delivery.

Further, as the number of providers has grown in relation to the number of regulatory staff, the process of monitoring providers has deteriorated. Extensive reliance by regulatory agencies on written documentation of provider compliance has become standard practice. The emphasis on paper compliance grew out of management systems theory, recognition of practical constraints on regulatory agencies, and difficulties involved in monitoring services in a decentralized system. With a multitude of providers and relatively few inspectors, the system allows regulators to rely on documentation rather than observation of the quality of services or measurement of outcomes. The practice has been widely criticized as unreliable (10,129,134).

Also, traditional quality assurance systems tend to use techniques that are more reactive than proactive, particularly regarding compliance mechanisms. Reactive mechanisms investigate service problems and rely on enforcement remedies or sanctions ensure compliance. Proactive mechanisms emphasize monitoring and assisting providers in improving practice and preventing problems.

Observations and criticisms of quality assurance mechanisms in the human services field are particularly relevant to long-term care. Demographic trends and increased need for long-term care, an increasingly debilitated population of older persons, fiscal constraints, and continuing concern about quality of care present serious challenges to policy makers, regulators, and providers alike. Although the existing regulatory system and increasing knowledge and skill among providers have led to improvements, much remains to be done to assure acceptable long-term care quality.

Several themes are central to a discussion of the possibilities for reform of the Nation's quality assurance system:

- **Structural and Process Standards:** Structural and process standards of care have contributed to improved long-term care quality and remain important components of a quality assurance system.
- **Outcome-Based Standards:** Quality assurance can be improved, both in terms of defining standards and monitoring compliance, by using quality measures that are resident-focused and more process- and outcome-oriented. In addition to specifying provider behavior in terms of expected structures and processes of care, standards and inspections could focus on the quality of care actually provided. One way of achieving that goal is to monitor and assess resident outcomes and, ultimately, specify desired outcomes.
- **Quality of Life Standards** could address outcomes and processes related to the quality of life, in addition to the quality of health and habilitative care. These may be particularly applicable to nursing homes and domiciliary care facilities.

- **Information:** A central element of a more effective quality assurance system is improved information. Both providers and regulators need substantial information about residents' characteristics:
 - Data about residents' conditions and needs are essential for determining necessary levels of resource inputs and appropriate processes of care, and for specifying and evaluating resident outcomes.
 - Such data are needed for effectively monitoring provider performance, for identifying factors leading to potential problems and unacceptable performance, and for correcting identified deficiencies.
 - For many outcome and process measures, the necessary data are identifiable, measurable, and accessible. Additional information is needed, however, to establish criteria for evaluating provider performance.
 - Information must be more systematically applied in developing standards of care and evaluation criteria.
 - A system for generating feedback of information on provider performance and state-of-the-art care is essential to a dynamic and evolutionary set of standards and criteria.
 - More information is also important for efforts to improve existing regulations. As noted, relatively little is known about the performance of home health agencies, adult day care programs, and respite care. Further, there is little systematic, empirical information about what interventions are effective, particularly in terms of the care and management of individuals with dementia. Thus it is difficult to determine whether existing standards, inspections, and enforcement mechanisms are effective or what kinds of quality assurance mechanisms would be more effective.
- **Enforcement:** Currently neither the regulatory system nor market mechanisms is effective for ensuring high-quality care. Regulatory compliance mechanisms have proved ineffective in enforcing standards. And consumers are hindered both by third-party payment systems and general inaccessibility to the legal process.

Several methods are available for assuring quality in long-term care, as discussed in the remainder of this chapter. Market forces, including competition and consumer empowerment, are one possible means. Provider quality assurance activities and professional peer review are other options. Improved regulatory systems are also possible, even in an era of fiscal constraints and deregulation.

Market Forces To Assure Quality

In a competitive "free" market, the issue of defining and regulating long-term care quality would be largely academic, interesting but not critical for assuring that people received high quality care. In such a competitive market, consumers would be informed, able to switch easily from one provider to another, and would allocate resources in such a way as to maximize their well-being. For long-term care, however, this model seems largely inapplicable.

Although reducing regulation and relying on competitive market forces are increasingly popular ideas, these mechanisms are seriously limited for ensuring quality care. Individuals who need nursing home or domiciliary care generally suffer from a bewildering array of physical, functional, and mental disabilities. Their ability to choose rationally among providers and, if dissatisfied with the quality of care, to switch from one provider to another, is hampered by several factors, including:

1. poor access to information;
2. limited ability to understand information;
3. restricted mobility;
4. a financing system biased toward institutional care; and
5. a vendor payment system that removes much of the decisionmaking from the consumer.

Once admitted to a nursing home or board and care facility, a resident is, in a very real sense, part of a "captive" population (193). That is, residents have little access to information and are generally unaware of other options. Further, with multiple disabilities and limited mobility, they can seldom exercise the option of leaving. This prob-

lem is exacerbated by the tight nursing home bed supply in most States (51)(65), Occupancy rates that average better than 95 percent make it difficult to find another facility, even when residents are capable of moving. Because of their restricted ability to leave, residents have little leverage even when they choose to complain to providers (70). For individuals with dementing illnesses, the problem of being an effective consumer is especially severe.

Families provide most long-term care themselves. When formal long-term care services are required, however, families are also hampered in their efforts to act as effective consumers. One significant difficulty they encounter is the absence of useful comparative information on the cost and quality of various long-term care settings. Such judgments are difficult even for professionals; for a family unschooled in measuring the quality of health care and under pressure to find help, meaningful evaluations are exceedingly difficult. Although trial and error is a theoretical solution to finding the best provider, it is inappropriate for someone needing long-term care.

Families are hindered by a variety of other factors, including financial constraints, the unwillingness of many long-term care providers to accept and properly care for individuals with dementing illnesses, and the general unavailability of appropriate long-term care services aside from nursing homes (134, 185). In addition, families are often pressured to make quick decisions about a long-term care provider, particularly when a hospital is seeking to discharge an elderly patient as quickly as possible.

These factors create serious difficulties for consumers of long-term care and their families who hope to use traditional market forces to assure the quality or accessibility of long-term care. Problems may be compounded for those who have no close relatives to assist them in pressuring providers to improve quality.

Given these problems, particularly the vulnerability of consumers, some argue that government has a fundamental role in assuring improved quality in long-term care. Further, they note, as the primary payer for most long-term care, especially for nursing homes and indirectly for board and

care, the government has an obligation to ensure that public monies are well-spent, that public funds are not spent on substandard care, and that public beneficiaries have access to long-term care of acceptable quality.

The practical difficulties of regulating and monitoring providers, however, give consumers an indispensable role in quality assurance. Regulatory standards, inspections, and enforcement mechanisms remain important, but the practical difficulties encountered by regulatory agencies, particularly in a decentralized system, mean that consumers and their advocates must take a strong role in quality assurance. Informed, empowered, and assertive consumers and advocates may hold the greatest potential for assuring quality in long-term care. Several mechanisms could strengthen the role of consumers and enhance their ability to use more traditional market mechanisms to assure acceptable long-term care quality.

Inspection/Survey Process

Consumers could be included in the inspection/survey process. Their views on the quality of care they receive from licensed and certified long-term care providers could be actively solicited by inspectors. That approach is most feasible in institutional settings; however, it is also possible for surveyors to telephone or visit a sample of home health and adult day care clients. For consumers with a dementing disorder, the surveyor could interview the person's family or, in an institution, members of the residents' council.

Consumer Advocates and the Legal Process

The role and powers of consumer advocates could be enhanced. That would be particularly appropriate for nursing home ombudsmen, whose legal authority covers both nursing homes and DCFs. Adequate funding for such ombudsmen, however, has not matched the expansion in their formal roles or the numbers of individuals who need their assistance in resolving disputes between long-term care providers and **consumers**. A recent Institute of Medicine report specified several recommendations for increased involvement of consumers and consumer advocates in quality assurance (79),

Consumer advocates might also be given the broader role of assisting consumers with all long-term care providers, including home health agencies, home chore service, adult day care, and in-home respite care,

The ability of long-term care consumers to use the legal process to enforce their rights to appropriate care and treatment could be enhanced through additional funding of legal services for elderly individuals.

information Dissemination

The ability of consumers and their families to be informed and effective could be enhanced by more systematic and widespread dissemination of information about case management, about evaluating the quality of care and services provided by long-term care institutions and agencies, and about mechanisms to remedy problems they encounter.

Revision of Residents' Rights

Federal nursing home regulations could be revised so that residents' rights are elevated to a condition of participation. The Institute of Medicine recommended such revisions and specified standards in some detail (79). Of course, the case of persons with dementia is especially difficult, since cognitive impairment inhibits their ability to assert and protect their rights. However, protection from transfers or discharges, and assertion of the rights of residents, their legal guardians, and their families, could enhance the effectiveness of long-term care consumers and their advocates.

Congress could amend the Social Security Act requirement that States establish and maintain standards for facilities in which three or more SSI recipients reside. In addition to standards specified in the Keys amendment, Congress could require that States establish residents' rights for individuals in DCFs.

provider Self-Review, Peer Review, and Professional Review

Another mechanism for improving and assuring the quality of long-term care involves the activ-

ities of providers and other health care professionals. Improved management among providers, more extensive training of direct care staff, and increased involvement of health professionals in nursing homes, for example, have had beneficial effects over the last two decades. Many long-term care providers are independently establishing internal quality assurance systems to monitor and improve their performance (see ch. 9). Further, professional groups, peer review organizations, and industry trade associations have made significant strides in encouraging long-term care providers to improve the quality of their services and the effectiveness of their monitoring systems.

Provider Self-Review

Several multistate nursing home organizations, including the National Health Corp., Hillhaven, Beverly Enterprises, and Ohio presbyterian Homes for the Aged, have developed internal quality assurance programs (79). These systems typically monitor some quality indices (e.g., staffing patterns, patient case mix, changes in patient status) that might suggest quality problems in their facilities. Some, such as Ohio presbyterian Homes, have developed detailed quality reviews that they routinely conduct in each of their facilities. These reviews include both resource input and process measures of quality. Hillhaven has been particularly active in attempting to develop standards for appropriate care and management of individuals with Alzheimer's disease.

Trade Association Review

Trade associations have begun encouraging members to establish standards for acceptable quality of care and to review their performances in a more systematic manner. The American Health Care Association's "Quest for Quality," for example, specifies matters that ought to be evaluated by nursing homes, suggests goals for quality performance, and provides quality review instruments.

The National Association for Home Care is also developing model standards to assist members in assuring that the care they provide meets acceptable professional standards of quality (56). At the State level, at least one State industry association

has refused membership to two providers whose nursing homes did not pass the association's peer review.

Professional Organization Review

professional organizations have also been active in long-term care quality assurance activities. The Joint Commission on Accreditation of Hospitals (JCAH) has had a voluntary accreditation program for nursing homes since 1966. Home health agencies that are hospital-based may also seek JCAH accreditation (56). The JCAH process emphasizes voluntary participation by providers, independent peer review, and professional responsibility, and includes continuing educational and consultation for providers seeking such accreditation (200).

The National League for Nursing (NLN) and the American Nurses Association's Division of Gerontological Nursing have been active in promulgating standards for long-term care nursing. Home health agencies seeking NLN accreditation must comply with standards defined by that organization. NLN also retains input and process measures for use in its ongoing evaluation of each agency's performance (56).

Associations like the National Council on Aging (NCOA) have become active in developing model standards for some long-term care providers. NCOA has developed a variety of suggested standards for adult day care programs. These are designed to augment adult day care licensure standards established in 39 States, which vary in content (from funding criteria to quality standards) and specificity. The NCOA standards address appropriate staffing patterns, structural and facility guidelines, and issues such as activities and administration. They specifically address issues related to appropriate care of individuals with dementia (141).

In some instances, private foundations have initiated efforts to improve quality of long-term care. The Robert Wood Johnson Foundation, for example, sponsors a teaching nursing home program to establish ties between nursing homes and schools of nursing and medicine. The foundation hopes the program will stimulate nursing facilities to improve their delivery of quality care and to develop internal quality assurance standards (2).

Data Collection Efforts

While self-regulatory activities by providers, peer review agencies, and health care professionals represent potentially beneficial developments in voluntary quality assurance, little is known about the efficacy of these programs (96). Of all the activities described, only the teaching nursing home program is being systematically evaluated in terms of its impact on quality of care (153). Although such efforts should be encouraged, reliance on them for quality assurance is probably misplaced until their impact has been empirically evaluated.

Regulation and Quality Assurance

Like the concept of "quality" itself, quality assurance in long-term care is complex and multidimensional. Quality of care is the product of many factors, including provider willingness and capacity to provide care, consumer characteristics and behavior, the role of consumer advocates, involvement of other health care professionals, third-party reimbursement policies, and the state of knowledge about effective treatment and care. It is also, in no small measure, the result of government policies aimed at assuring uniformly acceptable quality of care to elderly and chronically ill individuals.

Conceptual Model of a Regulatory Quality Assurance System

The primary components of a regulatory system for quality assurance are: 1) establishing standards of care; 2) monitoring compliance; and 3) enforcing compliance. The three are inextricably related. Without an adequate inspection system and mechanisms for enforcing compliance, standards of care can become meaningless. In addition, standards themselves must allow consistent, objective assessment and must be clear and fair enough to be enforceable in legal proceedings when necessary.

Several mechanisms have been suggested for strengthening the regulatory system for purposes of quality assurance. First, a richer definition of quality—one that is multidimensional, resident-focused, and outcome-and-process-oriented—would be valuable. Second, criteria for evaluation

ing the performance of long-term care providers might be defined. Third, an inspection system capable of assessing and rating quality of care could be established. Fourth, regulators could implement a system of incentives and disincentives for inducing compliance with at least minimal standards of care. Fifth, a process of collecting information for monitoring providers and modifying normative criteria could be implemented.

Developing Process and Structural Standards of Care

Professional and public perceptions of illnesses shape management and treatment (48,196). Because there is no cure for Alzheimer's disease and most other chronic dementing disorders, and because no single treatment has proved effective, many health care professionals and providers assume that relatively little can be done for persons with dementia other than providing food and shelter. That assumption leads to "warehousing" of these individuals, and contributes to the overuse of physical and chemical restraints,

Dementing disorders, like other chronic illnesses for which there is no cure, require careful management and planning. Although systematic research on the effectiveness of various management strategies is notably absent (81), the experience of many health care professionals and providers supports the argument that good management improves the functional, behavioral, and health status of individuals with dementia (see ch. 7).

Chapters 2 and 7 discuss management and treatment processes believed to be effective for persons with dementia (see box 10-B). These are important because, as discussed earlier in this chapter (in the section on defining quality), patient outcomes cannot be the only measure of quality in **long-term care**. These procedures could form the basis of recommendations for structural and process quality standards of care for a variety of long-term care settings, from nursing homes to adult day care programs,

Yet there is a dearth of research on the effectiveness of these techniques. They are largely the product of experience, often by trial and error,

Box 10-B.—Management and Treatment Procedures Effective With Individuals With Dementia

Medical Care.—All patients need an interested and informed physician, although frequent physician visits to patients with dementia may be unnecessary. Some researchers suggest that for persons with Alzheimer's disease, 4 to 6 months is an appropriate interval between examinations in the absence of a change in status or behavior (23,92). Current Federal standards specify that a nursing home is responsible for ensuring that appropriate physician visits are made to Medicare and Medicaid patients.

Diagnosis.—An adequate diagnosis is essential in order to rule out other factors that may cause memory loss and to ensure that, where Alzheimer's disease is present, other treatable disorders are identified and treated.

Hearing and Vision Care.—Decreased sensory input, resulting from poor vision or deafness, may aggravate existing confusion among persons with dementia. Medicare and Medicaid often do not cover hearing and vision examinations, or reimburse the purchase of sensory aids (e.g., eyeglasses and hear-

ing devices). Hearing and vision evaluations could be made standard components of medical care to be provided for those receiving long-term care.

Drugs.—Many different drugs (e.g., antidepressants, antipsychotics, and sleeping pills) are used to treat dementia and accompanying symptoms. Extreme caution and vigilance are imperative in administering drugs to someone with dementia, as many can have negative side effects (e.g., insomnia, confusion, hallucinations, agitation, or motor difficulties). It may be prudent to require that a physician or nurse authorize and monitor any drug administered to persons with dementia, eliminating prescription of drugs on an "as needed" basis.

Assessment and Individualized Care Plans.—Individualized assessment and care plans are important elements of adequate care. Ideally, these should be done by a multidisciplinary team and include an evaluation of the person's cognitive, functional, physical, mental, and emotional status. Peri-

odic updates are important to monitor status and identify effective features of care.

Communication. Individuals with dementia often suffer from several types of communication deficits. Caregivers thus learn how to communicate with the individual and how to interpret what could otherwise be considered as purposeful or liberally assaultive behavior. Specific techniques have been suggested for improving communication with persons with Alzheimer's disease (13,23).

Activity and Exercise. Many physicians prescribe active therapy rather than pharmacological approaches to the behavioral problems prevalent among persons with dementia, and recommend exercise and increased physical activity during the day to reduce restlessness and tension (23,24). Studies suggest that activity and exercise are vital not only to reduce wandering and restlessness, but also for physical health (44).

Maintaining Functional Capacity. Minimizing functional decline delays and helps prevent the physical problems associated with inactivity in addition to contributing to psychological well-being (44,68). A goal of long-term care, therefore, is to improve, maintain, or prevent avoidable decline in an individual's functional abilities, particularly in activities of daily living (e.g., eating, walking, and toileting).

Mental and Social Stimulation. Memory training and reality therapy are used in a number of settings in an attempt to offset cognitive deterioration experienced by persons with dementia. Techniques include review of names, date, and time; reminiscence exercises; and music therapy. These activities are thought to boost memory, self-esteem, and confidence in the environment (44,68,69).

Staff Training. Consistent staff training is crucial to behavior management for persons with

dementia. The physical layout of the environment, the staff-to-resident ratio, and the individualization of care are all factors in optimizing the effectiveness of managing behavioral problems (79).

Staff Shortages. Both institutional and family caregivers are often overwhelmed by the need to care for persons with dementia under constant surveillance. Effective precautions could be implemented to prevent falls, injuries, and other mishaps. These measures include having residents wear identification bracelets; placing locks at the bottom of stairs; attaching bells to exit doors; storing medications out of residents' reach; keeping cleaning agents and other toxic substances locked up; supervising residents who smoke, to prevent fires; keeping furniture in the same places; and removing clutter, cords, footstools, and other objects that are hazardous to someone with limited mobility (23).

Staff Training. Many observers argue that current standards for staff training in nursing homes, assisted living facilities, and community-based settings are inadequate (79), and that improved training, particularly in relation to care and management of individuals with dementia, is essential to improve the quality of care of these residents (23).

Staff-to-Resident Ratio. Federal regulations regarding staff-to-resident ratios are not specific, requiring only that "adequate staff" be present to meet the needs of nursing homes and assisted living homes; however, are not enough to assure that many experts believe is necessary for individuals with Alzheimer's disease and related disorders. A recent analysis suggests that a staff-to-resident ratio of 1 to 5 is appropriate for care of individuals with Alzheimer's disease and related disorders (63). The Institute of Medicine recommends ratios in U.S. nursing homes of 1 to 3, 1 to 10, and 1 to 15 (79).

among nurses, social workers, physicians, other health professionals, and family caregivers who have been providing care and services to persons with dementia over a period of years. Therefore, it is premature to suggest that these and similar techniques be incorporated into Federal regulations as mandatory procedural standards. But experience to date does suggest several options for congressional action:

- Federal regulations or State licensure laws could require every long-term care provider to conduct a multidimensional needs assessment and develop an individual care plan for each resident. The assessment could focus on physical health, mental status, and physical functioning. It could also include evaluation of sensory status; the care plan could include appropriate referrals.

- Every long-term care provider could be required to ensure that each person who exhibits signs of cognitive impairment be referred to an appropriate health care provider for further assessment and to a physician for a comprehensive physical examination (unless the person has already been seen by a physician).
- Every long-term care provider could be required to refer to a physician any person with dementia who exhibits sudden changes in physical, functional, or cognitive status. Further, the resident's chart/care plan should report such behavioral changes and the provider's course of action.
- Federal policy on payment for hearing, vision, and dental care (through Medicare and Medicaid) could be revised to mandate payment for needed appliances.
- Federal certification standards for nursing homes and State licensure laws for DCFs could be revised to include specific process of care standards on the appropriate use of physical and chemical restraints.
- Although exhorting States to improve licensure standards for DCFs is one possibility, Congress could also amend the Social Security Act, adding more specific guidelines to the requirement that States establish and maintain standards for facilities in which three or more SSI recipients reside. In addition to the items specified by the Keys amendment (admission policies, life safety, sanitation, and civil rights), the States could be required to ensure that each DCF resident receives appropriate personal and health care. Such an amendment could mandate that States require all licensed DCFs to: 1) conduct a routine needs assessment and develop a simple care plan for all residents; 2) establish relationships with social service and mental health agencies on behalf of residents; 3) assist residents in obtaining care for dental, vision, and hearing problems. States could also be required to develop process standards for the appropriate use of physical restraints and psychotropic drugs in DCFs.
- Federal certification standards could be revised to mandate preemployment staff training for nurse's aides. Further, the standards could more explicitly define the content of that training. The training could include specific information about dementias and effective management and treatment of individuals with dementing disorders.
- The Social Security Act could be amended to require that States establish training requirements for all supervisory and resident care staff in DCFs. (Only 25 percent of State regulations for DCFs require some form of staff training, and 27 percent require training for only some positions.) The training could include information on care and management of individuals with dementia (e.g., appropriate use and risks associated with psychotropic drugs and physical restraints, and effective treatment of communication and sleep disorders, wandering, agitation, and combative behavior).
- The Federal Government could encourage States and professional organizations to promulgate standards on appropriate staffing levels and training for noninstitutional long-term care programs (e.g., adult day care, respite care). Staffing standards that are case-mix sensitive may be particularly useful, since not all such programs serve clients with cognitive impairment and associated behavioral problems.
- Federal standards for staffing of nursing homes could be revised to require at least one registered nurse on duty in every nursing home for at least one shift every day. That requirement has been recommended by the Institute of Medicine (79).
- Federal nursing home standards could also be revised to eliminate the distinction between skilled nursing facilities (SNFs) and intermediate care facilities (ICFs). That is one of the most significant Institute of Medicine recommendations. The original perception was that ICFs and SNFs would serve distinct populations with significantly different care needs. In practice, that has not occurred; most facilities serve a mix of patients with varying disabilities and care needs. Moreover, individuals with dementia are typically cared for in ICFs. Yet, as discussed, while they do not typically require daily skilled nursing care, they do require the services of skilled nurses,

particularly in assessment, care planning, and supervision of care. The current guidelines for staffing in ICFs do not seem adequate to meet the complex care and supervision needs of residents with dementia.

- Federal standards for minimum nursing aide-to-resident ratios in nursing homes could be made more explicit. Current standards require staffing to be “adequate” to meet the needs of residents; but studies reveal that staffing levels seldom approach the 1 to 5 ratio suggested as appropriate for the care of someone with Alzheimer’s disease (63). Alternatively, guidelines for State survey agencies could specifically address the care needs of particular groups and methods of determining whether staffing is adequate, given a facility’s mix of residents.
- Congress could amend the Social Security Act to require that States establish staffing standards for DCFs. For example, Congress could require that DCFs hire a geriatric nurse practitioner or psychiatric nurse for a specified number of hours per week or month to review residents’ needs, to develop care plans, to review the use of any drugs or physical restraints, and to develop and coordinate arrangements with other social service or mental health agencies that provide services needed by the DCF residents.
- Congress could require that States report the results of their DCF admission policies and the findings of inspections. That would help determine whether individuals who require more supervision or nursing and personal care than DCFs can provide are nevertheless being housed in board and care facilities.
- Congress could establish a “look behind” authority for the Department of Health and Human Services to inspect DCFs in the States. In particular, DHHS could focus on whether some individuals who require nursing home care are being inappropriately housed in DCFs. Since most States have adopted measures to reduce the number of Medicaid recipients in nursing homes, they may have little incentive to prevent such inappropriate placement. Therefore, Congress might also consider monetary penalties against the States for any failure to adequately monitor DCF resident admission and retention.

Improving the Monitoring of Long-Term Care providers

Monitoring providers’ performance in relation to standards is the second critical component of a regulatory quality assurance system. The relationship between standards and inspection is reciprocal. Standards—the first component—must be amenable to objective measurement by inspectors, and must be administratively feasible for State and Federal agencies to implement. Similarly, many characteristics of the inspection system are influenced by the nature of the standards selected. Process or outcome quality standards, for instance, would demand considerably more of inspectors than structural or input-based standards, as the latter are relatively easy to quantify and measure objectively.

One suggestion for reform is the professionalization of agencies that perform facility inspections (12). That would be particularly critical if standards were based on process or outcome quality measures for which some subjective determinations would be unavoidable. Some aspects of the inspection system, however, are important regardless of the type of standards used. These include: timing, frequency, and type of inspection (e.g., announced/unannounced); size and composition of inspection teams (e.g., multidisciplinary teams, generalists); frequency and nature of surveys that validate inspections; and administrative structure and norms that support inspectors.

Reforming the survey process for nursing homes is the prerogative of the Federal Government, while States are responsible for DCF inspection standards. Several reforms could improve the inspection system for both types of institutions. Most of these reforms have been uniformly recommended in a decade’s worth of State reports,

As noted, as a result of *Smith v. Heckler*, the Federal Government is under court order to develop a survey process that is more resident-focused, and was to have introduced the Patient Care and Services (PaCS) System in August 1986. Several States have attempted to modify their licensure inspections, and Iowa has developed a resident-focused, outcome-oriented survey that is currently being evaluated (21,99,100). In general, however, such surveys do not include items directly related to the special care and service

needs of individuals with dementia. They could, however, be appropriately modified, particularly given the large and growing size of the nursing home population with some type of cognitive impairment (1080).

Surveys or inspections could be unannounced and scheduled to reduce the likelihood that providers could anticipate them. Some inspections, for example, could be conducted during the evening or on weekends, when they are unexpected and when deficiencies, such as short staffing, are thought to be most common (77,128,134,169).

Surveys, like regulations and performance standards, could be resident-focused and outcome- and process-oriented, rather than concentrating on structural features, facility records, and the capacity to provide appropriate care. Inspections could thus focus more on the care and services needed by and provided to residents. And, to the degree possible, they could focus more on residents' outcomes as initial indicators of quality of care and life in the facility. Surveys could include direct observation of residents (e.g., their personal grooming, use of physical restraints) and the care and services they actually receive (79).

Surveys may be made both shorter and more effective if they focus on key indicators of quality of care and quality of life. The outcome-oriented measures described earlier in this chapter could be used as some key indicators. Several States have experimented with a shortened, more focused survey process, and evaluations suggest that, to a large extent, such surveys are at least as effective in identifying deficiencies as the current process (40,99,109,130). A more effective survey process would allow agencies to concentrate inspection and enforcement resources on facilities with a history of poor care. Although all facilities ought to be inspected at least annually, poor facilities could be inspected more frequently (79).

One concern is that the key indicators of quality identified by those surveys may not be sufficiently comprehensive, particularly in describing mental health needs and care, quality of life, and process quality that are especially relevant to the care and management of individuals with dementia. Each of the existing systems could be evaluated to determine whether it includes significant

indicators of the care needed and received by someone with dementia. For such persons, the key indicators of quality that are outcome-oriented could include the items discussed in this chapter (e.g., overuse of physical restraints, overuse of psychotropic medications, personal care and grooming, dehydration). In addition, the survey could include some process measures of quality, since proper procedures of care and management for this population seem to be better developed than outcome-quality measures.

Under the current survey process, each facility receives the same inspection as all other facilities in the Medicaid or Medicare program with the same certification level (SNF or ICF). Given the diversity of facilities and of resident populations, such a system prohibits an effective orientation to individuals. For a more efficient and effective survey process, the survey instrument could be adjusted from facility to facility, based on the characteristics of the residents. Thus, for example, a facility with a high mix of individuals needing rehabilitative care would receive a slightly different survey from one with a high mix of persons with dementia. The outcome-oriented measures of quality for a stroke patient might focus on functional improvement, while for someone with dementia it might focus on drugs, restraints, and so on. A revised survey process and instruments could allow and encourage surveyors to focus on outcome and process measures specific to the nature and extent of individuals' disabilities and the resident mix of a given facility.

Although shorter, more focused surveys may be appropriate, a more extensive survey might be useful when inspections reveal quality problems. Identification of particular characteristics or outcomes may indicate where underlying problems exist in a facility. Negative outcomes—those not predicted given the residents' status or the mix of disabilities—could trigger a more extensive examination of a facility's resource inputs and processes of care. For instance, regulations may specify appropriate protocols for administering medications. If overmedication is discovered, further inspection might identify staff inadequacies or inappropriate processes of care as an underlying cause,

In most States, surveys are done by nurses or generalists. Only a few States have standard survey teams that include dietitians, physical and occupational therapists, pharmacists, physicians, social workers, psychiatrists or psychiatric social workers, and other professionals. Where surveys reveal problems in particular areas of care, specialists could be available to conduct more in-depth inspections. (For example, where an inspection team identifies problems in nutritional services, the agency could have a dietitian conduct a complete survey of resident nutritional status and the facility's dietary services.) Such specialists need not be included in every survey but could be on staff or under contract to the inspecting agency. The availability of psychiatrists, psychiatric social workers, and geriatric nurse practitioners experienced in assessing the care needs of persons with dementia would be particularly useful.

While such a process *would* entail increased inspection costs in some States, the increases could be minimal. Surveys that are more resident-focused and outcome-oriented are likely to be shorter than the current Federal survey process. Thus, some resources could be redirected to a more efficient and comprehensive survey of those facilities with quality problems.

Staff training could be improved, teaching **surveyors/inspectors** how to expand their focus beyond review of facility records to the direct observation of residents' conditions, care needed, and care received. In addition, training could include specific information on the state of the art in the care and management of individuals with dementia, including information assessment, care planning, and relevant outcome and process measures of quality.

The Federal Government could take more responsibility for the adequacy of survey staff, in terms of numbers, training, and experience. Alternatively, the government could provide funding to the States to monitor care in programs and facilities participating in Medicaid and Medicare.

Mere exhortation by the Federal Government has apparently been insufficient to elicit significant improvement in the inspection activities at State agencies. Increased Federal funding for these

purposes could raise State capabilities and give the Federal Government more authority and ability to demand improved performance. Although that would increase Federal costs, the increase would be a relatively small proportion of the funds now spent through Medicare, Medicaid, and SSI for care, and it would reduce the likelihood that those funds are being used to pay for substandard care.

Improving Enforcement Mechanisms

Even with improved regulator standards and a more effective survey and inspection process, effective enforcement—the third element of a quality assurance system—may be critical to improvements in marginal or substandard facilities. Inadequate enforcement appears to be national in scope. State survey agencies may apply formal sanctions only if a facility remains in violation beyond the deadline for compliance in the plan of correction (79). Formal sanctions thus become the last step in a long series of followup visits and plans of correction designed to induce compliance. Facilities are not punished for violating health and safety standards, but rather for failing to carry out an administrative order to correct violations. The result is that substandard homes may operate without penalty for more than a year even with serious violations of minimum standards.

Federal and State enforcement procedures could be modified to enhance the Federal role in ensuring the quality of nursing home care. Some options for more effective enforcement are authorized under Federal law and regulations; others do not exist under Federal oversight authority but have been used in a variety of States and could be incorporated into Federal regulations. These options include creating a range of sanctions or remedies that could be used in place of or in addition to consultation and recertification.

The Federal Government could encourage States to adopt a stronger enforcement posture and could make this feasible by: 1) separating the consultant and surveyor roles; 2) making survey followup procedures more specific; 3) creating a workable range of Federal sanctions and applying them more rigorously; and 4) increasing both Federal oversight and Federal support of State enforcement activities.

Consultation.—Federal regulations currently require survey agencies to advise facilities on how to improve their performance. In many States, surveyors are responsible for both consulting with and disciplining providers, despite the potential conflict in these roles. Several States, notably Washington, New York, and Connecticut, use separate agencies for consultation and enforcement; they consider the procedure successful. Survey agencies could examine their policy role and reorient the program toward enforcement rather than consultation.

Suspension of Payment for New Admissions.—The Omnibus Budget Reconciliation Act of 1980 gave authority to the Secretary of Health and Human Services to deny Medicare payments for new admissions to providers that are out of compliance with conditions of participation, so long as the deficiencies do not pose an immediate threat to the health and safety of the residents in the facility. The act assigns similar authority for Medicaid-only facilities to State agencies.

HCFA issued regulations to implement the law, which became effective in August 1986. These so-called intermediate sanctions regulations suggest that a State agency may recommend suspension of payments for new Medicare and Medicaid admissions for up to 11 months in a facility that has deficiencies that do not pose immediate threats to the residents' health and safety but do "require more emphasis than just a plan of correction." HCFA's New York regional office reports this mechanism to be effective in securing compliance with certification regulations. However, the regulation on suspension requires a full set of administrative hearings before the sanction takes effect (79). That makes the intermediate sanction nearly as difficult and slow to implement as decertification.

Before the regulations for bans on admission became final, a surveyor who found that a facility was consistently or repeatedly violating certification standards could choose only one sanction under the Federal programs: decertify the facility and recommend termination of a provider's contract. For the reasons previously cited, surveyors and State agencies hesitate to do that. Even with the intermediate sanctions in place, however, reform of enforcement process is badly needed.

Several options are possible. One of these is to examine and consider a facility's past record

Consideration of Past Record.—Federal regulations could be modified to allow States to sanction a facility by taking into account both the survey findings from prior years and those from the most recent survey. That modification would address the problem of the chronically substandard facility. States also need a method of weighting the seriousness of offenses that define repeat violations, matching sanctions to violations, and determining liability for offenses in order to effectively sanction repeat offenders. Statutory authority would be necessary to enable HCFA to prescribe procedures for States to follow in dealing with chronic or repeat violators. In addition, HCFA would have to develop criteria for determining who is responsible for repeat offenses. In determining such liability, HCFA and the States could use the definition of ownership applied under current Medicaid fraud statutes: any party having 5 percent or more interest in the facility, land, or deed. The current Minnesota State statute is a good example.

Many States have authority to use a variety of intermediate sanctions under State licensing laws. Some of these could be considered for adoption at the Federal level for violations of Medicare and Medicaid health and safety regulations. These include:

- **Suspension of Admissions:** Thirty-two States have the authority to deny payment or to prohibit new admissions to a facility. These sanctions can apply to all admissions, or only to Medicaid admissions, depending on the State.
- **Civil Fines:** Twenty-six States have the authority to assess a civil fine against a facility that fails to meet licensing standards. The amount of the fine varies according to the severity of the deficiency. Fines range from a few hundred to several thousand dollars. Of these States, 13 said they assessed fines in 1983; Florida, Wisconsin, and California were the most active. In general States view such penalties favorably, arguing that they are effective. Some State studies, however, report concerns that the amount of the fine would simply be made up by reduced expend-

itures on patient care (e.g., ref 134). Further, the exceptional length of the appeals process has limited the effectiveness of fines in some States.

- **Receivership:** In 21 States, when conditions pose an imminent threat to the health or safety of residents, a facility can be sanctioned by appointing a receiver to operate the facility. That is, the authority to operate a facility can be temporarily or permanently removed from the current owner or operator and granted by the courts to another person or group.
- **Conditional Provisional, and Probationary Licenses:** In several States a conditional or provisional license can be given for a limited time, during which time the facility is to correct licensing violations. The license is terminated if required corrections are not made.
- **Monitorships:** Seven States have authority to appoint a facility monitor. A monitor is assigned by the State licensure agency for a specified period to ensure that the facility's plan of correction is being implemented and that care of acceptable quality is being delivered to residents during the correction period.
- **Suspension/Withholding of Payment, Reduced Rates:** Suspension or withholding of payment, or reducing a facility's Medicaid rates, are ways of imposing financial sanctions. The period of suspension or reduction depends on when the facility comes into compliance. Texas uses "vendor hold" to stop all Medicaid payments to a facility that has serious, uncorrected deficiencies.
- **Criminal Penalties:** Thirty States have criminal penalties for violations of licensing laws. Generally, these penalties apply to violations of residents' rights and abuse of residents. Thirty-eight States also have laws making reporting of resident abuse mandatory. In a survey by the Institute of Medicine, only five States reported having used criminal penalties in 1983, when 376 actions were taken. Most of the actions took place in New York (79). In its 1984 survey of State licensure and certification agencies, the institute found that a total of 2,000 actions were taken against

some 15,000 facilities in 1983. Most of these (85 percent) were taken in 13 States. This statistic probably indicates that some States are more enforcement-oriented than others, not that facilities in these 13 States are consistently poorer providers than facilities in other States.

The Institute of Medicine findings regarding variations in the enforcement mechanisms used by States are significant for quality assurance. The institute found that the use of sanctions by a State is associated with several factors, including: 1) higher State appropriations for the State survey agency; 2) special training for surveyors in how to inspect nursing homes and gather evidence for enforcement proceedings; 3) a wider range and number of available sanctions; and 4) survey procedures that require greater numbers of facility visits or inspections each year. In essence, the situation appears to be a self-fulfilling prophecy: States committed to strong enforcement—in terms of personnel, resources, and procedures—were the most likely to develop and use sanctions. Thus, while Federal regulations could authorize a wider range of enforcement remedies and facilitate their use, the States must have some incentive to make effective use of these tools. options:

- Congress could consider providing additional funds to the States for enforcement activities. That procedure was quite successful with the 1976 Fraud and Abuse Amendments in encouraging States to set up special Medicaid vendor fraud units.
- Congress could consider developing a more meaningful way to sanction States that do not effectively monitor the performance of nursing homes and enforce compliance with Federal standards. The current provision, which involves cutting off all Medicaid funding, has the same limitations as nursing home "decertification"; it is too harsh for some violations and, because of its enormous consequences, it is not used even for serious failings. A more appropriate penalty might be a percentage reduction in the Federal share of Medicaid payments.

As noted, the weakest part of the Keys amendment to the Social Security Act board and care

provisions is that the penalty is taken against the SSI recipients—not against the facility that is violating minimum standards. Given the lack of direct Federal oversight, establishing effective enforcement mechanisms is difficult.

- Congress could consider modifying the Social Security Act to require that States develop an effective range of enforcement sanctions. Some of the sanctions previously discussed as options for nursing homes might also be effective for DCFs.
- Congress could also consider how it might encourage States to inspect DCFs effectively and enforce standards. Since monetary penalties seem to provide powerful incentives, some sort of fiscal incentive for States could be considered.
- Congress could consider providing special funds for States to upgrade their quality assurance system for DCFs. Specifically, funds could be targeted to training of inspectors, expansion of the inspection staff, and the development or expansion of existing enforcement staff (including both administrative hearing and prosecutorial staff).

Research and Quality Assurance

Research knowledge on issues of treatment and management of dementia is incomplete. Although individuals with dementia are widely believed to constitute the majority of long-term nursing home residents, and although most such individuals eventually need nursing home care, little is known about which management techniques are most effective. Health services research is needed if appropriate standards are to be developed for long-term care providers. Research on the following kinds of questions would be helpful in identifying problems, developing standards, and improving the quality assurance system in long-term care:

- How many nursing home residents suffer from Alzheimer's disease and other dementias? Currently this question cannot be answered with any precision, since families are reluctant to inform facilities of such a diagnosis, fearing the facility will discriminate in admission. Further, many residents are not accurately diagnosed.

- What kinds of behavioral problems (e.g., wandering, agitation, and combative behavior) are associated with dementia? More specifically, do they occur in combination? Do they occur only at certain times or in response to certain external stimuli (e.g., does wandering increase immediately after admission to a nursing home)? Answers to these questions would be helpful in informing nursing homes and adult day care programs, for example, about what kinds of behavior to expect and when is it most likely to occur.
- What kinds of interventions are most effective in dealing with behavioral problems? Interventions would include drugs, appliances, and management techniques. How might interventions vary by type of long-term care provider (e.g., nursing home v. community-based)?
- What kinds of interventions are most effective in dealing with other aspects of dementia (e.g., communication disorders, incontinence, and loss of functional abilities)? Although some information is available, there has been no systematic examination of the techniques used or comparison of the effectiveness of various approaches in long-term care settings.
- What staffing patterns are most effective for treating and managing individuals with a dementing disorder? More specifically, are different types of staff and staff/patient ratios needed at different stages in the course of diseases?

Little information is available on the number of individuals with dementia in facilities other than nursing homes. Perhaps of greatest concern are board and care facilities and unlicensed board and care homes, since regulatory standards and oversight of these institutions are sparse. Substantial research on both incidence and appropriate management would be appropriate:

- What proportion of individuals in DCFs have cognitive impairment, and how significant is that impairment?
- What other impairments (e.g., physical health and functioning) do cognitively impaired persons in DCFs have? How severe are those impairments?

- Do cognitively impaired persons in DCFs also have behavioral problems (e.g., wandering) that might place them at physical risk?
- Given the nature and severity of these impairments, what defines appropriate care (e.g., staffing, activities, drug review and administration, physical therapy)?
- Can DCFs currently provide appropriate care for the cognitively impaired persons residing there?
- How widespread is the use of physical and chemical restraints in DCFs? Are they used appropriately? Are residents at risk because DCFs are not equipped to deal with conditions or behaviors associated with dementia—except through physical restraints and psychotropic drugs?
- Are cognitively impaired persons transferred to nursing homes (or some other more appropriate setting) if and when the DCF cannot provide appropriate care?

In addition, the problem of individuals with fairly serious physical and cognitive impairments residing in unlicensed and unregulated homes, board and care homes could be addressed.

- Congress could mandate an in-estimation of the nature and seriousness of the problem, using the addresses of SSI recipients to identify unlicensed facilities.

It would also be useful to have more precise information about the effectiveness of various inspection processes and enforcement remedies. There is significant variation among the States in the numbers and types of individuals included in survey teams for nursing homes, DCFs, home health agencies, and adult day care programs; in how frequently inspections are conducted; in whether inspections are announced or unannounced; and in the focus of the surveys. Yet no study has compared the effectiveness of these approaches in accurately and completely identifying the nature and extent of violations or deficiencies. Similarly, though States vary in the availability and utilization of sanctions, no systematic comparison has been done of the effectiveness of various sanctions and enforcement attitudes on provider performance.

- Congress could consider requiring HCFA to provide funds to study the effectiveness of various inspection and enforcement processes.

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