THE NURSING HOME REFORM ACT OF 1987

Provisions, Policy, Prospects

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THE NURSING HOME REFORM ACT OF 1987

Provisions, Policy, Prospects

The quality of life experienced by anyone is related to that person's sense of well-being, level of satisfaction with life, and feeling of self-worth and self-esteem. For nursing home residents this includes a basic sense of satisfaction with oneself, the environment, the care received, the accomplishment of desired goals, and control over one's life.

Improving the Quality of Care in Nursing Homes

I. INTRODUCTION

When Congress enacted legislation in late 1987 to strengthen the protection of nursing home residents' rights, the new law was widely hailed as a major advance toward improving the quality of life of those residents. Its aim is to ensure that the care given to residents of nursing homes helps them reach the highest level of health and well-being possible and that their rights as individuals are respected by nursing homes and staff.

The law reflects a comprehensive focus on the resident: standards for nursing homes are based on the well-being of each resident. To judge whether a nursing home has met the standards, an inspection or survey of the facility will include interviews with residents. In all, the Nursing Home Reform law and regulations reflect a considerable change from the previous emphasis on process and procedures rather than the individual resident.

For years, stories had appeared in the media and had been told in numerous congressional hearings about poor conditions in many of the nation's nursing homes. These conditions seemed to persist despite a federal regulatory system for those nursing homes that participated in the Medicare and Medicaid programs — the majority of the nation's 16,000 facilities. The regulatory system consisted of rules written by the federal government, which were to be enforced through state monitoring of the facilities. Many critics charged that the regulations themselves and their enforcement by the states were inadequate and ineffectual. Even if state or federal surveyors, or inspectors, cited a nursing home for repeated violations, the only remedy was to shut it down, a process that could result in worse problems for residents who might have had no other place to go.

1Institute of Medicine, Improving the Quality of Care in Nursing Homes, National Academy Press, Washington, D. C. (1986), 51.
The impetus for reform of nursing home regulation was spurred on by major demographic changes facing the country. The U.S. population is aging — and with an older population comes the likelihood that many more Americans will spend some time in a nursing home. A recent study estimates that at least 43% of Americans of the 2.2 million who turned 65 in 1990 will enter a nursing home at some point in their lives, and 25% of those people will stay at least one year.2

And Americans are living longer. The number of Americans age 85 and older was 2.7 million in 1985; that number is expected to increase to more than 7 million by the year 2020. The likelihood of entering a nursing home increases with advancing age; in 1985, 45% of the 1.5 million nursing home residents were 85 and older.

This, then, was the backdrop for the 1987 Nursing Home Reform Act, often referred to as "OBRA 87" because it was incorporated into the Omnibus Budget Reconciliation Act of 1987, signed into law on December 22, 1987. The legislation was the product of about 10 years of work by a coalition of advocates, residents, and their families, as well as representatives of business, labor, and nursing home providers. The effort was spearheaded in large part by the National Citizens Coalition for Nursing Home Reform, which had been organized in 1975. The coalition represents 308 organizations, among which are the American Association of Retired Persons and the National Council of Senior Citizens.

The law provides a detailed list of requirements for nursing homes, ranging from assessing each resident's capabilities and weaknesses and planning programs of care based on those assessments to spelling out and expanding residents' rights to privacy, to voice grievances, and to be consulted about their care. The law also requires greater training of nurses' aides, who provide the bulk of the hands-on care for nursing home residents, and requires facilities to provide 24-hour licensed nursing services. In addition, the law authorizes tougher sanctions to be applied against nursing homes that fail to meet the new standards.

Although the law holds great promise for substantially improving the lives and well-being of nursing home residents, that hope is still far from being realized. Many obstacles face advocates for nursing home residents as they attempt to ensure that the law's new requirements become realities. The law was enacted late in 1987, but many of its provisions were not intended to go into effect until October 1990 — and guidelines from the federal government on how states and providers should carry out the requirements are still incomplete and/or subject to considerable controversy. Confusion, delays, and contention have marked the law's progress to date. Because of budget deficits, many states have been reluctant and slow to increase reimbursement rates to nursing homes to cover the additional costs that the facilities will incur as a result of the new law.

2Murtaugh, Christopher; Kemper, Peter; and Spillman, Brenda C., "The Risk of Nursing Home Use in Later Life," Medical Care 28, 10 (October 1990), 959-960.
For about a year until the spring of 1991, the nation’s largest state, California, kept insisting that it would not comply with the law because the federal regulations would merely duplicate what California was already doing, and at a cost to the state of an additional $400 to $600 million over what it was already spending. The dispute eventually resulted in negotiations between federal and state officials in March 1991 that has led to an apparent easing of the federal requirements. State officials were to be allowed more discretion to interpret federal guidelines than had previously been the case.

With all its problems, however, the law is considered a major step forward in the struggle to provide better care and ensure the rights of the more than one million nursing home residents, many of whom will spend their last days in a nursing home. Organizations that represent nursing homes have joined with advocates in applauding the law’s intent and goals. The American Health Care Association represents most of the nation’s nursing homes. The October 1990 issue of the Association’s magazine included an editorial stating that implementation of the law that month marked "a new era for the long term care industry. The nursing facility quality provisions . . . have the potential to have a dramatic impact on nursing facility residents and their quality of life."[3]

In that same issue, Elma Holder, executive director of the National Citizens’ Coalition for Nursing Home Reform, said, "When you look at it as a package today, OBRA is a major achievement in public policy. When it’s implemented, it will benefit each person that lives in a nursing home." The law centers on the nursing home resident, she said, "making it clear than an individual is entitled to rights, continuing rights as a citizen." The law also makes it possible, she continued, "for each individual to receive individualized personal care that should make a difference in the quality of care and quality of life on a day-to-day basis."[4]

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II. REGULATORY BACKGROUND

History

The federal government's involvement with nursing homes began in 1935 with the passage of the Social Security Act, which included a federal-state public assistance program for the elderly called Old Age Assistance. Many nursing home residents were public assistance recipients. But federal regulatory efforts were minimal for decades and state supervision through the licensing process little better. The Senate Special Committee on Aging, created in 1961, held hearings in 1965 that uncovered great variations in state nursing home standards and enforcement efforts.5

Also in 1965, the Medicare and Medicaid programs were enacted into law. To participate in the programs — that is, to be eligible for federal/state reimbursement for the care of Medicare and Medicaid beneficiaries — nursing homes were required to meet certain federal standards and procedures. The regulations were to be monitored by state health or welfare agencies through periodic surveys of the facilities.

Federal requirements at that time concentrated on two major areas: physical safety and written policies and procedures. Physical safety issues were called the "bricks and mortar" requirements. Critics of federal oversight of nursing homes contended that federal officials placed too much emphasis on these standards in those early years, ignoring quality of care. Even with the limited standards that had to be met to be certified for participation in Medicare and Medicaid, however, only 740 providers could be fully certified the first year after the regulations went into effect, out of 6,000 providers who applied.6

Federal Monitoring

Federal officials were not unaware of the limits of their efforts. Regulations for nursing homes under Medicare and Medicaid are the responsibility of the Bureau of Health Standards and Quality under the U.S. Health Care Financing Administration (HCFA). The Bureau's director, Thomas Morford, said in a 1988 article that the federal aim for nursing homes was "improvement in patient function, or at least no more deterioration than was unavoidable." But, he continued, "we could not mandate good results through regulation, and the state-of-the-art was such that the idea of regulating for outcomes was little more than a hope for the future."7

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5Institute of Medicine, pp. 240-41.

6Institute of Medicine, op. cit., p. 241.

Through the development of regulations and the issuance of surveyors’ manuals and surveying guidelines, the federal agency advised states on how to conduct surveys of nursing homes to see that facilities were adhering to federal standards. Surveyors would visit nursing homes that participated in Medicare and Medicaid, often unannounced, armed with a standardized form including questions to ask of the management and staff and conditions to check. Their reviews ranged from observing the sanitation of the facility’s kitchen to determining whether residents were receiving appropriate medical treatment. In summary, they were to investigate whether the physical plant was safe, the staffing appropriate, and the residents being adequately cared for.

But the development of regulations and the existence of a survey process were not enough to satisfy the public and government officials that all nursing homes were providing quality care to their residents. Reports of problems continued to be aired in congressional hearings, newspaper and magazine articles, and official government reports. The Senate Special Committee on Aging held hearings in the early 1970s that led to a 1974 series of reports critical of federal regulatory efforts.8

Another set of regulations governing nursing homes was put into place in 1974, but they satisfied few people — neither consumer advocates nor the nursing home operators or administrators. Consumer advocates contended that the standards were inadequate and enforcement too lax. Violations of residents’ rights were not detected or were ignored by regulators, said the advocates. On the other hand, providers argued that regulations required too much detailed documentation, contained too much specificity about structural technicalities, and provided too many ambiguously worded standards.9

But rather than make standards and enforcement more stringent, the Reagan Administration in 1982 as part of its efforts toward deregulation proposed to ease requirements on Medicare and Medicaid-certified nursing homes. The Administration backed off, however, when consumer groups strongly objected, and Congress threatened to enact a moratorium on all federal rulemaking related to nursing homes. HCFA’s next step was to commission the National Academy of Sciences’ Institute of Medicine (IOM) to study nursing home regulation and make recommendations.

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9Institute of Medicine, op. cit., pp. 6-7.
III. INSTITUTE OF MEDICINE REPORT

The Institute of Medicine (IOM) report issued in 1986 made an immediate and forceful impact on the debate over the need for nursing home reform. Here was a committee of distinguished and influential people under the auspices of a prestigious institution confirming the anecdotal information that had been accumulating for years about the state of federal regulatory efforts in regard to nursing homes.

The 415-page report concluded that nursing home residents were receiving "shockingly deficient" care. "More effective government regulation could substantially improve quality in nursing homes," the report said. It contained a copious list of recommendations that ranged across a variety of issues — residents' rights, quality of care, staffing and training, and survey and certification, to name several. Many of the recommendations found their way into the final nursing home reform legislation enacted a year later. In fact, the IOM report has been called the blueprint for the legislation.

The report called for a "major reorientation" of the regulatory system to "make it focus on the care being provided residents and the effects of the care on their well-being." This would require, the report said, revision of nursing home performance criteria and standards (the "conditions of participation" and "standards" nursing homes had to meet to participate in Medicare and Medicaid). It would also mean revision of the survey process and enforcement policies and procedures.

Nursing homes should be required periodically to assess the health and well-being of each resident, the report said, and should ensure that each resident received "high-quality care to meet individual physical, mental and psychosocial needs." In addition, the report listed a series of civil and personal rights of nursing home residents that the facilities should be required to honor, including informing residents in advance of any transfer or discharge that the facility was planning for individuals and residents being given the opportunity to inspect their own medical records.

About six months before the IOM report was released, the Department of Health and Human Services had published a proposal for a new outcome-oriented survey process based on interviews with and observations of residents. Two months after the publication of the report, the department issued its final regulations, with resident interviews now a key part of the survey and inspection process.
The Nursing Home Reform Act, enacted as part of the Omnibus Budget Reconciliation Act of 1987, requires nursing homes to meet specific standards to qualify for Medicare and Medicaid reimbursement. The law requires states to take into account the costs of the new law when setting Medicaid reimbursement rates for nursing homes.

The law also eliminates the distinction under Medicaid between skilled nursing facilities (SNFs) and intermediate care facilities (ICF), effective October 1, 1990, with all the facilities now to be called "nursing facilities" (NFs). (The SNF designation still remains under Medicare.)

The following is a summary of the major provisions.

**Requirements for Care** — Sections 1819(b), Medicare, and 1919(b), Medicaid

* Nursing facilities must conduct a comprehensive assessment of the condition of every person admitted and develop a written plan of care describing the medical, nursing, and psychosocial needs of the resident and indicating how those needs will be met. [Sections 1819(b)(3) and 1919(b)(3)]

* At least once a year, an assessment must be made of each resident's ability to perform daily living activities, such as dressing and eating.

* States must conduct preadmission screening and annual resident reviews to detect for mental illness or mental retardation. Individuals identified as being mentally ill or mentally retarded must not be placed or remain in the facility unless they also need nursing care and/or have been a resident of the facility for at least 30 months. If a mentally ill or mentally retarded resident remains in the nursing home, he or she must be given appropriate mental health treatment. [Section 1919(b)(3)(F), (e)(7), and (f)(8)]

* Facilities must provide or arrange for the following services: physician, nursing, rehabilitative, pharmaceutical, dietician, dental, and medically related social services. A program of activities for residents must be offered. [Section 1919(b)(4) and 1919(b)(4)]

* The same quality of service must be provided to all residents, regardless of their source of payment. [Section 1819(c)(4) and 1919(c)(4)]
Residents’ Rights — Sections 1819(c), Medicare, and 1819(c), Medicaid

When admitted to a nursing home, residents are to be informed both in writing and verbally of their legal rights, which include the rights to:

* choose one’s own physician and be consulted on a plan of care, including the right to refuse treatment;

* be free from chemical and physical restraints;

* enjoy privacy and confidentiality of personal and medical records and protection of personal funds;

* voice grievances without fear of reprisal and gain prompt attention to and resolution of those grievances;

* organize and participate in residents’ groups, with family members able to meet in family groups;

* have access to federal or state surveys of the facility and to a local or state long-term care ombudsman, and

* receive services with reasonable accommodations of individual needs and preferences.

Staffing and Training — Sections 1819(b),(e),(f) and 1919(b),(e),(f)

* Facilities must have at least one registered nurse (RN) on duty eight hours a day, seven days a week, and a licensed nurse on duty 24 hours a day, seven days a week. [Sec. 1819(b)(4)(C) and Sec. 1919(b)(4)(C)]

* States may waive the nurse staffing requirements if a facility can show diligent but unsuccessful efforts to recruit the required personnel.

* Facilities with more than 120 beds must employ at least one full-time social worker.

* Nurses’ aides or nursing assistants must undergo at least 75 hours of approved training and pass a competency evaluation. States must develop and maintain registries of those aides who have satisfied the requirements and any aides who have been found to have abused or neglected residents. [Sec. 1819(b)(5), (e)(1-2), (f)(2)]
Survey and Certification — Sections 1819(g) and 1919(g)

* States must conduct unannounced "standard" surveys of nursing homes at least once a year, but no less often than every 15 months. An "extended" survey will be carried out at any facility found to be providing substandard care.

* Surveys are to include an audit of a sample of resident assessments and interviews with residents to determine the quality of care being provided.

* States must set up procedures to investigate complaints about violations of standards.

Enforcement and Sanctions — Sections 1819(h) and 1919(h)

* A state or the federal government can immediately appoint a temporary manager or end a facility’s participation in Medicare or Medicaid if a facility is found to be out of compliance and to be posing a danger to the health or safety of its residents.

* Intermediate sanctions can be applied to facilities that are out of compliance but that are not jeopardizing the health and safety of residents. Those sanctions include:

  a) denial of payment for new Medicare and/or Medicaid admissions;
  b) civil penalties of $10,000 a day for each day the facility is out of compliance, and
  c) appointment of a temporary manager.

* Denial of payment for new admissions will be automatic if a nursing home is found to be out of compliance for three consecutive months.
V. IMPLEMENTATION ISSUES

Regulatory Delays and Legislative Changes

Advocates for nursing home reform spent years pulling together the coalition for reform and gaining the support in Congress that led to final passage of the Nursing Home Reform Act. In the years since, they may have come to wonder if getting the law’s provisions in place and enforced is going to take as least as long as enactment.

Although implementation dates for various provisions of the law were spread out over several years, nursing home owners and state governments contended that the law still did not allow them enough time to put into effect what are in many cases complex and costly requirements. The task has been made more difficult by federal government delays in publishing regulations and guidelines and by further changes enacted by Congress in 1989 and 1990. An omnibus regulation was issued in February 1989, but strong objections by advocates and providers to many of its provisions forced HCFA to delay several proposed implementation deadlines and to redraft several sections of the regulations. Many provisions of the law eventually went into effect with no regulations in place.

The following summarizes the status of regulations and guidelines for the various sections of the law, as of July 1991.

Requirements for Care. Two of the most difficult areas of the new law in terms of framing regulations have been the requirement for preadmission screening and annual resident reviews (PASARR) of the mentally ill and mentally retarded and the requirement for comprehensive assessments of all other residents.

The federal government was to have developed the criteria for PASARR by October 1, 1988. HCFA published guidance materials for the states in October 1988 and in May 1989, but Congress found it necessary to instruct HCFA in 1989 legislation to issue proposed regulations on preadmission screening and resident reviews by March 19, 1990, a deadline which the agency met.

Then in 1990, lawmakers modified the definition of mental illness under PASARR to target only residents or applicants with serious disorders. Providers had feared that the original definition of mental illness as "a primary or secondary diagnosis of mental disorder" was too broad and would cover too many people with only minor dysfunctions. HCFA was required under the 1990 legislation to develop a new definition of mental illness for purposes of PASARR in consultation with the National Institute of Mental Health.

The 1990 legislation also allowed nursing homes to assess residents within 14 days after admission, rather than within four days as in the original bill.
Another issue holding up final regulations has been the Minimum Data Set (MDS) system developed by the federal government for use in comprehensive assessments of residents. The MDS information form collects considerable information about residents, from their drug regimen to how they perform activities such as dressing and eating. A debate has arisen among HCFA officials and others over whether to require computerized reporting of this data to state and federal agencies. Those who favor the idea say such information could be extremely useful to surveyors, among others, to help them target investigations on facilities whose reports indicate high levels of inappropriate or unsatisfactory conditions among their residents. Others contend, however, that computerized reporting would violate residents’ rights to privacy and confidentiality since a considerable amount of information on their cases would become available to persons outside the nursing home.

Proposed rules on PASARR requirements were published March 23, 1990; federal officials expected to publish final regulations in the summer of 1991. A proposed rule on comprehensive resident assessments was moving through the federal review process during the spring of 1991.

Residents’ Rights. The majority of the issues concerning residents’ rights were addressed in the February 1989 “final” regulations that HCFA issued as a "Final Rule with Request for Comments," which became effective August 1, 1989. (HCFA has said it would respond to the comments in a "Final Final" rule on residents’ rights and other issues, expected by late summer 1991.)

Regulations on physical/chemical restraints are currently part of a proposed "omnibus" rule that also addresses psychopharmacological drugs, monitoring of nurse staffing waivers, and state requirements in regard to resident rights under Medicaid. Federal officials say the omnibus rule will also be published in the summer of 1991.

Staffing and Training. In the Omnibus Budget Reconciliation Act of 1989, Congress extended the deadline from January 1, 1990 to October 1, 1990 for states and facilities to comply with the requirement for nurse aide training and competency evaluations. Lawmakers also stipulated that states must offer nurses’ aides alternatives to a written examination and could establish a program for evaluating an aide’s performance of specific tasks at the nursing home that employed the aide.

The legislation also allowed states to waive the competency evaluation for aides who had worked for the same employer for at least 24 consecutive months before the law was enacted. Also, a nurse’s aide would be considered to have satisfied the training and competency evaluation requirements if he or she had completed a training course of at least 100 hours and had been judged competent before July 1, 1989.

In 1990 legislation, Congress expanded the number of nursing homes allowed to conduct the training of their own nurses’ aides. As originally written, the law had precluded facilities with any deficiencies in the past two years from providing such
training. (A nursing home is cited for having a "deficiency" if an inspector determines that the facility has not met certain standards.) Providers argued that the majority of nursing homes would fail to be free of any deficiencies for a two-year period (particularly since deficiencies can relate to relatively minor as well as major issues), and thus most would be precluded from conducting their own training. Under revised provisions, nursing homes are now excluded from providing training only if they have been subject to an extended survey or have been cited for extensive deficiencies.

Another provision of the 1987 law allowed states to grant waivers to nursing homes for either the registered nurse or the licensed nurse requirements but not both. The 1990 Omnibus Budget Reconciliation Act changed that provision to allow waivers to be granted for both standards. But any nursing home that is granted such a dual waiver must notify the state ombudsman and residents.

Final regulations on nurse aide training and nurse staffing waivers were awaiting approval at the federal Office of Management and Budget in the spring of 1991.

Survey and Certification/Enforcement. The February 1989 regulations specified that the new inspection system for nursing homes would go into effect August 1, 1989, while the law itself had not required that the new system be in place until January 1, 1990. State officials said the shorter deadline would not give them enough time to train inspectors. As a result of considerable pressure from state officials and providers, HCFA backed off and postponed the deadline.

Proposed rules on survey, certification, and enforcement were still working their way through the federal government in the spring of 1991, with publication not expected for several months. Federal officials say final regulations probably will not be published until late 1991 or early 1992. In the meanwhile, state officials have been working with interpretative guidelines issued by HCFA.

Costs

The federal and state governments share the costs of the Medicaid program with the federal split being between 50 to 70%, depending on a state’s per capita income. The states each determine a rate schedule for nursing homes in the states that pay a per diem amount for each Medicaid resident. These rates varied in 1989 for skilled nursing homes from a high of $126.20 in New Hampshire to a low of $34.89 in Arkansas, with the average being $70.06.

OBRA 87 included language requiring the states to adjust reimbursement rates to nursing homes to take into account the extra costs of the new requirements. In March 1990, HCFA directed the states to submit by April 1 amendments to their payment plans for nursing homes and to provide assurances that their payment rates would reflect the new costs. But many states were slow to respond, contending that
they did not have the money to raise reimbursement rates significantly. Congress tried again in technical amendments to the 1990 Omnibus Budget Reconciliation bill by requiring state Medicaid plans to include a detailed description of the specific methodology used to adjust reimbursement amounts.

In 1988, the Congressional Budget Office (CBO) estimated that the federal government would spend an additional $832 million over the next five years just for the increased staffing and training requirements of the law and that the states would have to spend an extra $572 million.\(^{10}\)

**Staffing**

The new law requires a nursing home to have a licensed nurse on duty throughout the day, seven days a week, and to have a registered nurse on duty for eight hours a day. While advocates and nurses' organizations said these requirements would upgrade the care of residents, nursing home operators said the rules were unrealistic and unattainable given a national shortage of nurses and the difficulties that nursing homes have had in attracting licensed nurses. Nursing homes are said to pay from 20% to 50% less for an RN than does an acute-care facility, such as a hospital. A facility's nursing staff on average is 15% registered nurses, 14% licensed practical nurses, and 71% nurses' aides, according to the Institute of Medicine.\(^{11}\)

The American Nurses' Association (ANA) reports that nearly one in five registered-nurse positions was unfilled in 1990 at 999 nursing homes surveyed by ANA.\(^{12}\) Early in 1991, Paul Willging, executive vice president of the American Health Care Association, estimated that a third of the nursing homes in some states would not be able to recruit enough nursing staff to meet the requirements of the law.\(^{13}\)

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\(^{11}\)Institute of Medicine, op. cit., pp. 89-90.

\(^{12}\)Staff Shortages Hurting Nursing Homes the Most," American Journal of Nursing, January 1991, p. 90.

\(^{13}\)Push to 'Reform' Long-Term Care Seen 'Starting Off on Crutches,'" American Journal of Nursing, January 1991, p. 85.
VI. QUALITY OF CARE

Some harbor the hope that nursing home care can be revamped with the right form. Alas, it is hard to find such a panacea these days. The unlikelihood of miracles is not cause for pessimism, however. The work . . . to develop a standardized form for nursing home assessments . . . represents a major step forward in improving care.

The Gerontologist

Resident Assessments

The Nursing Home Reform law states that a resident must be given "appropriate treatment and services to maintain or improve on his or her ability to ambulate, dress, feed, groom, bathe, toilet, transfer and communicate."

The way nursing homes are to determine whether "appropriate treatment and services" are being provided and whether residents "maintain or improve" their ability to function is through resident assessments. Each nursing home must carry out a "comprehensive, accurate, standardized, reproducible assessment of each resident’s functional capacity." The purpose of the provision is to prevent "warehousing" of residents, whose condition could deteriorate from lack of attention. A nursing home will not be judged through the survey process mainly on its potential to provide care through its written policies and procedures as in the past, but on actual care that is given to the resident and the results of that care.

The residential assessment should be a useful instrument for nursing homes to gauge condition and functioning of residents, and will be a critical element when inspectors evaluate quality of care. For example, has the resident’s condition deteriorated since she entered the nursing home, and if so, in what ways? Or is she now functioning better than when she arrived, as for example by walking on her own or by dressing herself when she could not manage those activities without help before? How has the facility assisted the resident to attain and maintain his highest practical physical, mental, and social well-being?

Since the law took effect, all nursing homes have been required to conduct a comprehensive evaluation of each person when he or she is admitted to the facility and annually thereafter, as well as when any significant change occurs in the status of any resident. The assessment should help describe "the resident’s capability to perform daily life functions and significant impairments in functional capacity." The

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nursing home must use the assessment "in developing, reviewing, and revising the resident's plan of care." That plan is to be developed with the participation of the resident, if possible (or the resident's family or legal representative), and by a team to include the resident's attending physician and a registered professional nurse.

A key part of a resident assessment will be the minimum data set system (MDS) that will be used to detail a resident’s strengths, weaknesses, and problems, and other information about the resident's physical and cognitive abilities and behaviors. For example, the MDS will chart a resident’s prior medical history, functional status, comprehension, vision and hearing abilities, communication skills, ability to engage in activities, rehabilitation potential, and drug therapy.

Many experts in the field of gerontology applaud the idea of a standardized assessment as an opportunity to improve care by providing nursing staff with meaningful information about a resident’s condition, and whether and how that condition changes over time.

**Preadmission Screening and Annual Resident Review**

One of the most controversial features of the Nursing Home Reform Act is the provision for preadmission screening and annual resident review of individuals with mental illness or mental retardation. The purpose of the reviews is to identify whether a nursing home is the appropriate placement for a given individual with mental illness or mental retardation. The assessment should help determine whether an applicant or a resident should perhaps be in a less restrictive environment such as a board and care home, or needs more specialized mental health treatment than can be provided in a nursing home.

What led to the drafting of the PASARR requirement was a concern by advocates and others that the mentally ill and mentally retarded in many cases were not receiving the correct care in nursing homes. This might happen because these individuals either did not need the nursing services provided by a nursing home and might have benefitted from a more independent setting or because, on the other hand, they had serious mental problems which required more aggressive treatment.

However, many state officials, providers, and mental health professionals feared that the new screening requirements would result in large numbers of mentally ill and mentally retarded persons being turned away or discharged from nursing homes with no other place to go. Also, Medicaid pays for care in a nursing home for many of these individuals; the program does not generally cover group homes or halfway houses.

The number of people who would be affected by the screening requirement hinged on two controversial issues: the broad definition of "mental illness" in the law as written and the inclusion of private-pay residents in the assessments. The law says
that before a mentally ill or mentally retarded applicant can be admitted to a nursing home — a person paying with private funds as well as someone whose care would be covered by Medicare or Medicaid — that person has to be tested to determine if the nursing home is the most suitable place for his or her care. For residents of a nursing home, a review is to be carried out annually to ensure that a person's condition has not changed to such an extent that nursing home care is no longer appropriate.

A mentally ill or mentally retarded applicant can be admitted to the nursing home if he or she needs nursing facility services (including occupational or physical therapy). A resident can stay in the home if he or she continues to need nursing services or has been a resident for at least 30 consecutive months. But if a resident remains in the facility while needing active treatment for mental health problems, then he or she must be provided that kind of treatment.

The first stage of PASARR, or "Level I" as it is being called, is a determination of which individuals should be classified as "mentally ill" or "mentally retarded." Then a "Level II" determination must be made about whether those defined as mentally ill or mentally retarded require nursing services and/or active mental-health treatment.

The original language of the law defined mental illness as applied to nursing home residents as a "primary or secondary diagnosis of mental disorder." The only exclusions were persons with a primary diagnosis of dementia, such as Alzheimer’s disease. Providers in particular argued that the broadness of that definition would force them to screen a very large number of people with only minor mental illnesses. Finally, after several years of attempts to amend the law, it was changed in late 1990 to define mental illness as "serious disorders."

On the issue of excluding private-pay residents from the PASARR requirements, providers were not as successful in changing the law, despite attempts in successive sessions of Congress. The PASARR requirements apply to all residents of Medicaid-certified nursing homes, including those who pay for their care with their own funds.

In any event, the impact of PASARR may not be felt for several years. States can propose alternatives to the transfer of residents who are found to need active mental-health care, or request that transfer or active treatment be postponed for a certain period of time. Forty-six states requested and were granted approval for alternative plans.15

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VII. QUALITY OF LIFE

One of the key features of the Nursing Home Reform Act is the delineation of the rights of nursing home residents. Although previous federal regulations included a list of residents’ rights to be respected by nursing homes, the new law establishes those rights in statute, and goes beyond those earlier regulations in its prohibitions against indiscriminate use by nursing homes of physical and chemical restraints.

Physical and Chemical Restraints

"... facilities must promote and protect the rights of each resident," including "the right to be free from ... any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the resident's medical symptoms."

Nursing Home Reform Act

Physical Restraints. Physical restraints include straps, bed railings, hand mitts, vests, and wheelchair safety bars, which are all used to limit a resident’s ability to move. Some providers insist that physical restraints are used in the best interest of residents — to hold those people in beds or in chairs who might otherwise fall through weakness or dizziness and injure themselves or to hold those who might wander off. Nursing home operators also fear they will be legally liable if a resident gets hurt.

Advocates for nursing home residents, on the other hand, contend that restraints are mainly used for the convenience of staff and for the economic bottom line of the nursing home — fewer residents moving around means fewer aides who have to be hired to watch them or engage in activities with them.

According to federal surveys, about 41% of all nursing home residents were put in physical restraints in 1989, up from 25% in 1977.17 In a report issued in March 1991, the Commission on California State Government Organization and Economy said physical or chemical restraints were being used on between 68% and 80% of California’s 120,000 nursing home residents.18

The use of restraints had become the norm in many nursing homes, and the policy was seldom questioned. One New Hampshire advocate of removing restraints

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16Sec. 1819(c), "Requirements Relating to Residents’ Rights."


said that staff often could not remember why restraints were being used on particular residents. "We find that a lot of patients have been left in restraints for so many years that when you ask why the patient is restrained, nobody knows," she said. "So these patients need to be released from restraints to see if they're still behaving the way they did years ago when they were put in restraints in the first place. They need to be re-evaluated in terms of why they were restrained and how long the restraint has just been a part of their everyday care."19

Chemical Restraints. Chemical restraints are the drugs, sedatives, or other medications administered to residents to keep them quiet, calm, or sleepy. A 1988 study by a team of researchers from Harvard Medical School found that 58% of 850 residents of 12 Massachusetts nursing homes were on drugs such as tranquilizers and sleeping pills. Many of the residents were being given excessive doses of the drugs and more than one drug at the same time, according to the researchers. "Suboptimal choice of medication . . . was common," the Harvard researchers said. Drugs for schizophrenics were frequently given, for example, to elderly patients.20

Chemical and physical restraints are sometimes used in combination on nursing home residents. Since certain drugs or medications can lower blood pressure and make a resident faint or unstable, the physical restraints might be used to make sure the resident is relatively immobile. Nursing home administrators also point to the high percentage of residents of nursing homes today who are in their eighties or nineties and who suffer from dementia and mental confusion. Residents with dementia can sometimes be violent and kick or bite nursing home staff or other residents. However, critics of heavy drug use say the drugs themselves can make residents more confused or agitated.

The law states that antipsychotic drugs are to be used only if they are deemed necessary to treat a specific condition under a valid psychiatric diagnosis and are administered on orders of a physician as part of a written plan of care. Residents must not be given drugs in excessive doses for excessive periods of time without being monitored or be given drugs in the absence of a diagnosis that warrants the use of the drug. (HCFA uses the word "excessive" in its interpretative guidelines for surveyors without defining it, but the agency says it is developing further guidelines which will include specific drugs and dosages.)

Under the new law, nursing homes must not restrain patients for purposes of discipline or convenience. When HCFA first issued guidelines on the restraint provision, the government agency said that a nursing home would have to secure a resident's consent before using any restraints. Surveyors were to check on whether a nursing home had evidence of consulting with appropriate health professionals such as


occupational and physical therapists before applying restraints. But in April 1991, the agency appeared to be backing away from that position. HCFA sent out revised guidelines to the states that said inspectors would not have to determine whether residents had given their consent to be restrained or whether the nursing home had tried other methods.

Personal Autonomy

The ability to make choices and exercise control over their lives, treatment with dignity, and positive caring attitudes by staff emerged as the critical elements . . . underpinning most of the other issues residents raised.

A Consumer Perspective on Quality Care

The words above come from a 1985 survey report of nursing home residents which asked them about the quality of their lives in nursing homes and what changes they would most like to see. The overwhelming problem that a nursing home resident faces, many of them said, was maintaining personal autonomy in an institutional setting.

The residents’ rights provisions of the new law try to ensure that some degree of personal autonomy and choice will be given residents. When people enter a nursing home, the facility must inform them both orally and in writing of their rights and all the facility’s rules that will affect them. If the individual cannot understand English, the information must be provided in a language that the person does understand. The person must acknowledge in writing that he or she received the information. A resident also must be informed in advance of changes to be made, such as a change of room.

Records concerning residents must be kept confidential. The resident has the right to receive mail unopened and to participate in resident councils. The law also requires that certain parties have immediate access to residents, including the resident’s attending physician, immediate family and other relatives, and surveyors or ombudsmen. The resident has a right to deny access, however, to family members or visitors, and a facility may impose limited restrictions on certain other visits.

Transfer and Discharge. A nursing home cannot transfer or discharge a resident unless:

* the nursing home cannot meet the needs of the resident; for instance, the resident requires a higher level of medical care than the facility can provide,

* the health or safety of other residents would be endangered if the resident remains,

* the resident or another party responsible for payment has not paid the resident's bills, after reasonable and appropriate notice, or

* the nursing home closes its doors.

The resident must generally be given 30 days notice before a transfer or discharge, except if a health or safety issue involves the other residents or she or he has a health emergency that requires a quicker move. And a nursing home must provide "sufficient preparation and orientation to ensure safe and orderly transfer or discharge."

Self-Determination and Participation. HCFA has sought to bolster the quality-of-life requirements of the new law by providing surveyors with questions to ask residents about the choices they are allowed in regard to daily activities. Nursing homes must make reasonable accommodations to the needs and preferences of residents. These types of questions include:

* Do you usually get up in the morning and go to bed at night at a time of your own choosing?

* Is your sleep interrupted by anyone during the night? Why?

* Can you eat other than during scheduled meal times? With whom do you eat? Is that your choice?

* Can you choose what you wear? How are you groomed?
VIII. THE FUTURE OF NURSING HOME REFORM

Although several years have passed since the nursing home reform legislation was enacted, progress and change under the new law is difficult to ascertain yet because of the many delays in implementation and other challenges to the law. However, the passage of time has also made it clear to nursing home providers that major legal and regulatory changes are coming — and many facilities have already begun altering their practices. For example, the National Senior Citizens Law Center reported in March 1991 that the new law had already reduced the use of restraints in nursing homes by 25%.

A key factor in getting results under the law, however, will be the willingness and ability of state governments to enforce the law’s provisions. The cautious embrace of the law by many states reflects a deep concern on the part of their governors about skyrocketing expenses under the Medicaid program. A large part of a state’s Medicaid funds go to nursing homes for the care of low-income persons (as well as middle-income people who are forced onto Medicaid when nursing home costs exhaust their savings and exceed their income). Many governors see the new nursing home provisions as just one more in series of federal mandates that they can little afford.

For example, in February 1991, the Governor of California, Pete Wilson, in refusing to administer the new nursing home law contended that the federal government was "improperly attempting to mandate standards on the states." In a letter to President Bush, Wilson argued that state requirements adequately protected nursing home residents in California. In a lawsuit against the federal government filed on March 1, 1991, the state said that the federal government had illegally tried to "mandate costly and unnecessary nursing home standards." The state said in the lawsuit that it refused "to comply with these illegal pronouncements."

As mentioned earlier, California officials said the new requirements would cost the state Medicaid program an additional $400 million to $600 million a year, only half of which would be reimbursed by the federal government. The California Medicaid program was already spending $2 billion annually on nursing home care under Medicaid, half of which the state had to pay. In an analysis of the costs of the new law, state officials wrote: "We do not consider that there are improvements in care which justify the increased cost."

Although the state contended that its program was equivalent to the federal government’s new standards, a federal district judge disagreed with that assertion in a February 1991 ruling on a separate class action lawsuit on behalf of nursing home patients filed by the National Senior Citizens Law Center and others. Judge Edward J.

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22Spiegel, "Restrains, Drugging Rife in Nursing Homes," op. cit.
Garcia noted that California law permitted the use of drugs to restrain or control behavior. He said nursing home patients in California were suffering irreparable harm as a result of California’s failure to implement the new law.23

Since the state refused to inspect nursing homes under the new standards, the Health Care Financing Administration decided to send more than 100 federal investigators to California to carry out the inspections. In addition, the federal government had withheld $24 million in Medicaid money from the state.

California was not the only state to balk at implementing the new nursing home rules and regulations. Kentucky, Pennsylvania, Ohio, and West Virginia said they lacked the funds to meet the new mandates. One major complaint involved the almost 200-page manual that HCFA issued as "Interpretive Guidelines" for state inspectors to follow on each survey of a nursing home. State officials said the considerable level of detail in these guidelines would create a sizable workload for the inspectors. California said its form for surveyors was only 40 pages long.

California and federal officials finally hammered out an agreement under which the state took back its enforcement responsibilities, and was apparently free to use discretion in interpreting the federal guidelines. State and federal officials were going to be working together, they said, to review and revise the interpretative guidelines that the state found burdensome. The guidelines would be considered "tools" for inspectors rather than "requirements," federal officials said.

The decision left other states wondering how their responsibilities had changed, if at all, and advocates concerned that the reform law was being weakened before it even got off the ground. Advocates said they feared that federal officials seemed to be giving state inspectors much greater leeway in using their own judgment about specific guidelines than advocates believed advisable. As an example, Pat McGinris, the executive director of California Advocates for Nursing Home Reform, pointed out that it was not the law but the guidelines that spelled out the exact conditions under which chemical or physical restraints could be used.24

Indeed, HCFA officials said they would be notifying all states that they planned to "review and revise" the guidelines to make it clear that the guidelines were not mandatory. But they insisted that the wording revisions they would make were only minor — for example, changing the word "must" to "may" where necessary. Those kinds of changes, said many advocates, could gut the law by allowing inspectors essentially to ignore many of its provisions, and nursing home operators to challenge any attempts made to impose sanctions.

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However, three serious challenges to the law's effectiveness remain:

* the lack of financial resources available to states and nursing homes,

* the ability of the states to effectively implement and enforce the law, and

* the lack of final regulations and guidelines.

How these questions will be resolved remains to be seen in the coming months and years. Still, for all the contention and controversy that has swirled around the Nursing Home Reform Act since 1987, it marks a major step forward in the effort to improve the lives of nursing home residents. The debate over many of its provisions has helped focus attention once again on the plight of many of these residents and has more directly than ever before emphasized the commitment of the U. S. Congress for change in nursing homes.
APPENDIX

THE NURSING HOME POPULATION IN 1987

SUMMARY: The majority of nursing home residents in 1987 were female, white, no longer married, and over age 80. More than half of the residents needed assistance with four or more activities of daily living (ADLs) and over 42% had some form of dementia. Over 20% had been in the facility for more than five years and almost 70% had been a resident for more than one year.

* In 1987, slightly over 1.5 million persons lived in nursing homes or personal care homes, of whom more than 45% were age 85 and older.\(^2\)

* Only about 5% of persons over age 65 live in nursing homes, but the figure rises to 22% for the 85-and-over population.

* Over 73% of all nursing home residents were women in 1987. Of the women in nursing homes that year, 51% were age 85 or older.

* The majority of nursing home residents are white (90.8%), while 7.5% are black.

* About 21% of nursing home residents in 1987 had been in the facility in which they were living for five years or more.

* Male nursing home residents were more likely than women residents to have short stays in a facility -- 13.6% of the men

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\(^1\) The source for the above information on nursing home residents in 1987 is Tamra J. Lair and Doris C. Lefkowitz, Mental health and functional status of residents of nursing and personal care homes, National Medical Expenditures Survey Research Findings 7, Agency for Health Care Policy and Research, U.S. Public Health Service, September 1990.

\(^2\) A larger number of persons are admitted to nursing homes each year, but about one third of those admitted are discharged within three months. They leave for home, for a hospital or rehabilitation facility, or they die.
had been in the nursing home for 90 days or less compared to 9.7% of the women.

* More than a third of women residents between the ages of 85 and 89 had been in the nursing home from one to three years; 18% had been a resident for five years or more.

* Almost 59% of nursing home residents in 1987 had limitations in four or more activities of daily living; 61% of women had difficulties with at least four ADLs compared to 52.7% of men.

* The greatest problem for those who needed assistance with ADLs was dressing themselves -- 76% of residents needed help with this activity. Over 63% needed assistance toileting and almost 39% could not eat without help.

* Of elderly nursing home residents aged 85 to 89, 35% suffered from dementia while over 14% had dementia in combination with a mental disorder and another 9% had a mental disorder only.

* Almost two thirds of nursing home residents showed symptoms of depression and nearly 30% showed psychotic symptoms.
REFERENCES


Nursing Home Reform Act. (How do we put this in a Ref list?)


THE GERONTOLOGY INSTITUTE

The University of Massachusetts at Boston

Established in 1984, the Gerontology Institute at the University of Massachusetts at Boston furthers the University’s commitment to the study and development of social policy on aging. The Institute conducts policy research on issues affecting older people and their families. In addition, the Institute assists national, state, and local organizations analyze policy issues and formulate policy options on matters concerning the elderly. Core funding is provided by the Massachusetts Legislature. Major projects are funded through grants and contracts.

Programs of the Institute are carried out through two divisions: The Frank J. Manning Research Division and the Public Policy Division. A major research priority is productive aging, that is, opportunities for older people to play useful social roles. A second priority is long-term care for the elderly. Additional major concerns of the Public Policy Division include health care policy, income security policy, and housing, with particular attention to the special needs of racial and ethnic minority elderly.

In the fall of 1990, the University introduced a Ph.D. program in Gerontology with an emphasis in social policy. It is one of two such programs in the country. The Institute is a teaching resource for the Ph.D. program. In addition, the Institute provides doctoral students with experience in research and policy analysis.

The Institute also supports the University’s Gerontology Certificate program. A one-year program of concentrated study, the Gerontology Certificate program prepares older learners for roles in aging services. Most students are over 60 years of age. Through an Advanced Certificate program, selected graduates participate in applied research projects within the Institute. The regular involvement of older people helps to assure that Institute projects reflect the concerns of older people.

Another activity of the Institute is the publication of a scholarly quarterly with an international perspective, the Journal of Aging & Social Policy. The journal is issued by Haworth Press.

Since its formation, the Institute has been directed by Scott A. Bass, Ph.D. It has a permanent faculty and staff of approximately 16 people and is located in the heart of Boston in the University’s Downtown Center.