

Chapter 5

Regulations And Guidelines For Special Care Units

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Regulations And Guidelines For Special Care Units

INTRODUCTION

In response to concerns about the diversity of existing special care units, the lack of standards to assist families, nursing home surveyors, and others in evaluating the units, and widespread allegations that some special care units provide nothing special for their residents, six States have developed regulations for special care units, and other States are in the process of doing so. The Alzheimer's Association has developed legislative principles for special care units to assist States in formulating regulations. In addition, the Alzheimer's Association and many other public and private organizations have developed or are in the process of developing guidelines for special care units.

These regulations and guidelines are or would be superimposed on the existing regulatory structure for nursing homes—a complex, multi-layered structure that includes six major components:

- Federal regulations for Medicare and Medicaid certification of nursing homes,
- State licensing regulations for nursing homes,
- State certificate of need regulations for nursing homes,
- other State and local government regulations that apply to nursing homes,
- the survey and certification procedures associated with each of these types of regulations, and
- the oversight and advocacy procedures of each State's Long-Term Care Ombudsman Program.

In addition to these six components, Federal, State, and local government regulations for nursing homes incorporate standards established by private organizations, such as the National Fire Protection Association's Life Safety Codes. Because these standards are incorporated into government regulations, they become part of the regulatory structure. Lastly, about 5 percent of nursing homes in the United States choose to be accredited by a private organization, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) (214). These nursing homes are surveyed by JCAHO and must meet JCAHO standards, as well as Federal, State, and local government requirements.

The regulatory structure for nursing homes is currently undergoing massive changes due to the implementation of the nursing home reform provisions of the 1987 Omnibus Budget Reconciliation Act (OBRA-87). The provisions of OBRA-87 pertain to the Federal regulations for Medicare and Medicaid certification of nursing homes and the survey and certification procedures associated with those regulations, but the changes mandated by OBRA-87 are so extensive they affect other components of the regulatory structure as well.

This chapter describes the existing regulatory structure for nursing homes, including the changes mandated by OBRA-87. It discusses State regulations and other State policies for special care units. It also describes the guidelines for special care units that have been developed or are being developed by various public and private organizations.

The policy question addressed by the chapter is whether there should be special regulations for special care units. On the one hand, the rapid proliferation of special care units, the lack of standards to help families, nursing home surveyors, and others evaluate the units, and the pervasive allegations that some special care units provide nothing special for their residents argue for the development of regulations. On the other hand, the current lack of agreement about the particular features that are necessary in a special care unit and the lack of research-based evidence of the effectiveness of any particular features make it difficult to determine what the regulations should say beyond general statements about goals and principles and a listing of the issues that require special consideration in the care of nursing home residents with dementia (e.g., physical design, staff training, security, activity programs, family involvement, and resident rights).

As this chapter points out, many of the Federal Medicare and Medicaid regulations mandated by OBRA-87 are directly relevant to the complaints and concerns expressed by families and others about the care provided by most nursing homes for individuals with dementia. The OBRA regulations rarely mention cognitive impairment or dementia, but the resident assessment system developed to implement

OBRA-87 focuses on the assessment of a resident's cognitive status and the identification of problems and care needs that are common among nursing home residents with dementia. OBRA regulations require that residents' needs be assessed, using this or a similar assessment system, and that once their needs are identified, appropriate services be provided to meet those needs.

The regulations for special care units now in effect in six States were not developed in the context of the new OBRA regulations. The six States' regulations address some common areas, but their requirements in each of these areas vary, and each State's regulations include requirements for features not included in the other States' special regulations. Moreover, some of the requirements are very specific. The inclusion of requirements for particular features in special care unit regulations implies that these features are important in the care of nursing home residents with dementia; that other features which are not required by the regulations are not important in the care of these residents; and that the limited resources of nursing homes should be expended for the required features rather than other features. As yet, however, there is no consensus about the particular features that are necessary in a special care unit and no evidence from research to support requirements for any particular features.

OTA concludes from the analysis in this and the preceding chapters that from a Federal perspective, the objective of improving nursing home care for individuals with dementia will be better served at present by initiatives to develop greater knowledge and agreement about the particular features that are important in the care of nursing home residents with dementia, to determine how those features fit into the regulatory framework created by OBRA-87, and to support and monitor the implementation of OBRA-87 than by the establishment of new Federal regulations for special care units. Many of the same considerations that lead to this conclusion would seem to apply equally to the development of State regulations for special care units.

THE EXISTING REGULATORY STRUCTURE FOR NURSING HOMES

Nursing homes are said to be among the most highly regulated entities in this country (201). Federal, State, and local government regulations apply to virtually all facets of nursing homes'

physical design and operation. Nursing homes are inspected at least annually by surveyors or teams of surveyors who evaluate the facilities' compliance with one or more of these types of regulations. Staff members or volunteers representing the State's Long-Term Care Ombudsman Program also visit nursing homes to investigate and resolve complaints about resident care. This section describes each of the components of the regulatory structure.

Federal Regulations for Medicare and Medicaid Certification of Nursing Homes

The legislation that created the Medicare and Medicaid programs gave the Federal Government the authority to establish requirements for nursing homes that choose to participate in the programs. Nursing homes must be certified as meeting these requirements in order to receive Medicare or Medicaid payment for any of their residents. As of 1985, 75 percent of the nursing homes in this country were certified for Medicare, Medicaid, or both, and these facilities accounted for 89 percent of all nursing home beds (467).

The requirements for Medicare and Medicaid certification of nursing homes have been changed several times in the past two decades, most recently as a result of OBRA-87 and amendments to OBRA-87 enacted since 1987. Prior to the implementation of OBRA-87, there were separate certification requirements for *skilled nursing facilities (SNFs)* participating in the Medicare and Medicaid programs and *intermediate care facilities (ICFs)* participating in the Medicaid program. Effective in 1990, OBRA-87 eliminated the distinction between SNFs and ICFs for Medicaid purposes. A single set of requirements for Medicaid certification of *nursing facilities (NFs)* is now in effect. Separate but very similar requirements for Medicare certification of SNFs are also in effect (456,225).

The current requirements for Medicare and Medicaid certification of nursing homes were first published by the Health Care Financing Administration (HCFA) in February 1989 (462). The final version of these requirements was published by HCFA in September 1991 (463). The requirements address residents' rights, residents' quality of life, resident assessment, care planning, staff credentials, staff training, use of physical restraints, use of psychotropic and other medications, quality of care, nursing, physician, dietary, social work, dental, and

rehabilitative services, activities, handling of residents' funds, record-keeping, physical plant, preadmission screening, and other areas.

Many of the requirements are directly relevant to the complaints and concerns of families and others about the care provided by most nursing homes for individuals with dementia. (See table 1-1 inch. 1 for a list of these complaints and concerns.) The most relevant of the requirements are quoted here from the September 1991 version of the "Requirements for Long-Term Care Facilities" (463).

- "The facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each residents quality of life."
- "The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality. '
- "The facility must conduct initially and periodically a comprehensive, accurate, standardized, reproducible assessment of each resident's functional capacity.'
- "The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet are-sident's medical, nursing, mental, and psycho-social needs that are identified in the compre-hensive assessment. '
- "A comprehensive care plan must be prepared by an interdisciplinary team, that includes the attending physician, a registered nurse with responsibility for the resident, and other appropriate staff in disciplines as determined by the resident's needs, and to the extent practicable, the participation of the resident, the resident's family or the resident's legal representative. '
- "Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physi-cal, mental, and psychosocial well-being, in accordance with the comprehensive assessment and plan of care. '
- "Based on the comprehensive assessment of a resident, the facility must ensure that a resi-dent's abilities in activities of daily living do not diminish unless circumstances of the indi-vidual's clinical condition demonstrate that diminution was unavoidable.'
- "Based on the comprehensive assessment of a resident, the facility must ensure that a resident whose assessment did not reveal a mental or psychosocial adjustment difficulty does not display a pattern of decreased social interaction and/or increased withdrawn, angry, or depres-sive behaviors, unless the resident's clinical condition demonstrates that such a pattern was unavoidable.
- "The facility must provide for an ongoing program of activities designed to meet, in accordance with the comprehensive assess-ment, the interests and the physical, mental, and psychosocial well-being of each resident."
- "If specialized rehabilitative services, such as but not limited to physical therapy, speech-language pathology, occupational therapy, and health rehabilitative services for mental illness and mental retardation, are required in the resident's comprehensive plan of care, the facility must:
 1. provide the required services, or
 2. obtain the required services from an outside...provider of specialized rehabil-itative services. '
- "The resident has the right to be flee from any physical or chemical restraints imposed for purposes of discipline or convenience, and not required to treat the resident's medical symp-toms.'
- "Each resident's drug regimen must be free from unnecessary drugs. An unnecessary drug is any drug when used:
 1. in excessive dose (including duplicate drug therapy); or
 2. for excessive duration; or
 3. without adequate monitoring; or
 4. without adequate indications for its use; or
 5. in the presence of adverse consequences which indicate the dose should be re-duced or discontinued; or
 6. any combinations of the reasons above. "
- "Based on a comprehensive assessment of a resident, the facility must ensure that:
 1. residents who have not used antipsy-chotic drugs are not given these drugs unless antipsychotic drug therapy is nec-essary to treat a specific condition and documented in the clinical record, and

2. residents who use antipsychotic drugs receive gradual dose reductions and behavioral interventions, unless clinically contraindicated in an effort to discontinue these drugs.”
- “The facility must provide: a safe, clean, comfortable, and home-like environment, allowing the resident to use his or her personal belongings to the extent possible...(and including) adequate and comfortable lighting levels in all areas; comfortable and safe temperature levels; ..(and) comfortable sound levels. ’
 - “The resident has the right to retain and use personal possessions, including some furnishings, and appropriate clothing, as space permits, unless to do so would infringe upon the rights or health and safety of other residents. ’
 - “A facility must not use any individual working in the facility as a nurse aide for more than 4 months, on a full-time, temporary, per diem, or other basis, unless:
 1. that individual has completed a training and competency evaluation program, or a competency evaluation program approved by the State, and
 2. that individual is competent to provide nursing and nursing-related services. ’
 - “The facility must provide regular performance review and regular in-service education to ensure that individuals used as nurse aides are competent to perform services as nurse aides. *In-service education must include training for individuals providing nursing and nursing-related services to residents with cognitive impairments*” (463) (emphasis added).

With the exception of the last requirement, none of these requirements mentions cognitive impairment or dementia. Many of the requirements refer, however, to residents’ needs as identified by the required comprehensive assessment. If the comprehensive assessment identifies the needs of residents with dementia, the regulations require that these needs be met.

OBRA-87 mandated the development of a set of core items to be addressed in the required comprehensive assessment. In 1988, HCFA contracted with a consortium of researchers at Research Triangle Institute, Hebrew Rehabilitation Center for Aged, Brown University, and the University of Michigan to develop a resident assessment system that would

include these core items (308). The resulting assessment system consists of two parts: 1) the Minimum Data Set, a 5-page resident assessment instrument, and 2) 18 Resident Assessment Protocols that provide additional information to assist nursing home staff members in assessing and developing care plans for residents with certain problems (309). States may use this assessment system or develop one of their own, provided the system they develop incorporates the core items (308).

The Minimum Data Set emphasizes the assessment of a resident’s cognitive status. Six questions about cognitive status appear on the first page of the assessment instrument, immediately after the basic identifying information about the resident (309). (Fig. 5-1 shows the first page of the Minimum Data Set.) Other sections of the assessment instrument include questions about problems and care needs that pertain particularly to residents with dementia. One section asks, for example, whether the resident needs ‘supervision, including oversight, encouragement, or cueing’ in order to perform activities of daily living (309). Another section asks about mood problems (e.g., agitation and withdrawal) and behavioral symptoms (e.g., wandering, verbal and physical abusiveness, and socially inappropriate or disruptive behavior). That section also asks whether the “behavior problem has been addressed by a clinically developed behavior management program. . . (not including) only physical restraints or psychotropic medications” (309). Other sections ask about the resident’s customary routine, the resident’s involvement and preferences in activities, the number of medications he or she is taking, the number of days in the preceding week he or she has received antipsychotic, antianxiety, or antidepressant medications, and the frequency of use of physical restraints.

A one-page form to be used for quarterly review of a resident’s comprehensive assessment also emphasizes cognitive status and certain problems and care needs that pertain particularly to residents with dementia (309). The form includes questions about memory, cognitive skills for daily decision-making, behavioral symptoms, the number of days in the preceding week the resident has received antipsychotic, antianxiety, or antidepressant medications, and the frequency of use of physical restraints. It also repeats the question about the resident’s need for “supervision, including over-

MINIMUM DATA SET FOR NURSING HOME RESIDENT ASSESSMENT AND CARE SCREENING (MDS)
(Status in last 7 days, unless other time frame indicated)

SECTION A. IDENTIFICATION AND BACKGROUND INFORMATION

1	ASSESSMENT DATE	<input type="text"/> <input type="text"/> <input type="text"/> — <input type="text"/> <input type="text"/> <input type="text"/> — <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
2	RESIDENT NAME	(First) (Middle Initial) (Last)	
3	SOCIAL SECURITY NO.	<input type="text"/> <input type="text"/> <input type="text"/> — <input type="text"/> <input type="text"/> <input type="text"/> — <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	
4	MEDICAID NO. (if applicable)	<input type="text"/>	
5	MEDICAL RECORD NO.	<input type="text"/>	
6	REASON FOR ASSESSMENT	1. Initial admission assess. 2. Hosp/Medicare reassess. 3. Readmission assessment 4. Annual assessment 5. Significant change in status 6. Other (e.g., UR)	
7	CURRENT PAYMENT SOURCE(S) FOR N H STAY	Billing Office to indicate, check all that apply Medicaid <input type="checkbox"/> VA <input type="checkbox"/> Medicare <input type="checkbox"/> Self pay/Private insurance <input type="checkbox"/> CHAMPUS <input type="checkbox"/> Other <input type="checkbox"/>	
8	RESPONSIBILITY/LEGAL GUARDIAN	Check all that apply Legal guardian <input type="checkbox"/> Family member responsible <input type="checkbox"/> Other legal oversight <input type="checkbox"/> Resident responsible <input type="checkbox"/> Durable power attorney/health care proxy <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	
9	ADVANCED DIRECTIVES	For those items with supporting documentation in the medical record, check all that apply Living will <input type="checkbox"/> Feeding restrictions <input type="checkbox"/> Do not resuscitate <input type="checkbox"/> Medication restrictions <input type="checkbox"/> Do not hospitalize <input type="checkbox"/> Other treatment restrictions <input type="checkbox"/> Organ donation <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/> Autopsy request <input type="checkbox"/>	
10	DISCHARGE PLANNED WITHIN 3 MOS.	0. No 1. Yes 2. Unknown/uncertain	
11	PARTICIPATE IN ASSESSMENT	a. Resident 0. No 1. Yes b. Family 0. No 1. Yes 2. No family	
12	SIGNATURES	Signature of RN Assessment Coordinator Signatures of Others Who Completed Part of the Assessment	

SECTION B. COGNITIVE PATTERNS

1	COMATOSE	(Persistent vegetative state/no discernible consciousness) 0. No 1. Yes (Skip to SECTION E)	
2	MEMORY	(Recall of what was learned or known) a. Short-term memory OK—seems/appears to recall after 5 minutes 0. Memory OK 1. Memory problem b. Long-term memory OK—seems/appears to recall long past 0. Memory OK 1. Memory problem	
3	MEMORY RECALL ABILITY	(Check all that resident normally able to recall during last 7 days) Current season <input type="checkbox"/> That he/she is in a nursing home <input type="checkbox"/> Location of own room <input type="checkbox"/> NONE OF ABOVE are recalled <input type="checkbox"/> Staff names/faces <input type="checkbox"/>	

= Code the appropriate response = Check all the responses that apply

COGNITIVE SKILLS FOR DAILY DECISION-MAKING	(Made decisions regarding tasks of daily life) 0. Independent—decisions consistent/reasonable 1. Modified Independence—some difficulty in new situations only 2. Moderately Impaired—decisions poor; cues/supervision required 3. Severely Impaired—never/rarely made decisions	
INDICATORS OF DELIRIUM—PERIODIC DISORDERED THINKING/AWARENESS	(Check if condition over last 7 days appears different from usual functioning) Less alert, easily distracted Changing awareness of environment Episodes of incoherent speech Periods of motor restlessness or lethargy Cognitive ability varies over course of day NONE OF ABOVE	
CHANGE IN COGNITIVE STATUS	Change in resident's cognitive status, skills, or abilities in last 90 days 0. No change 1. Improved 2. Deteriorated	

SECTION C. COMMUNICATION/HEARING PATTERNS

1	HEARING	(With hearing appliance, if used) 0. Hears adequately—normal talk, TV, phone 1. Minimal difficulty when not in quiet setting 2. Hears in special situations only—speaker has to adjust tonal quality and speak distinctly 3. Highly impaired/absence of useful hearing	
2	COMMUNICATION DEVICES/TECHNIQUES	(Check all that apply during last 7 days) Hearing aid, present and used Hearing aid, present and not used Other receptive comm. techniques used (e.g., lip read) NONE OF ABOVE	
3	MODES OF EXPRESSION	(Check all used by resident to make needs known) Speech <input type="checkbox"/> Signs/gestures/sounds <input type="checkbox"/> Writing messages to express or clarify needs <input type="checkbox"/> Other <input type="checkbox"/> NONE OF ABOVE <input type="checkbox"/>	
4	MAKING SELF UNDERSTOOD	(Express information content—however able) 0. Understood 1. Usually Understood—difficulty finding words or finishing thoughts 2. Sometimes Understood—ability is limited to making concrete requests 3. Rarely/Never Understood	
5	ABILITY TO UNDERSTAND OTHERS	(Understanding verbal information content—however able) 0. Understands 1. Usually Understands—may miss some pertinent of message 2. Sometimes Understands—responds adequately to simple, direct communication 3. Rarely/Never Understands	
6	CHANGE IN COMMUNICATION/HEARING	Resident's ability to express, understand or hear information has changed over last 90 days 0. No change 1. Improved 2. Deteriorated	

SECTION D. VISION PATTERNS

1	VISION	(Ability to see in adequate light and with glasses if used) 0. Adequate—sees fine detail, including regular print in newspapers/books 1. Impaired—sees large print, but not regular print in newspapers/books 2. Highly Impaired—limited vision; not able to see newspaper headlines; appears to follow objects with eyes 3. Severely Impaired—no vision or appears to see only light, colors, or shapes	
2	VISUAL LIMITATIONS/DIFFICULTIES	Side vision problems—decreased peripheral vision (e.g., leaves food on one side of tray, difficulty traveling, bumps into people and objects, misjudges placement of chair when seating self) Experiences any of following: sees halos or rings around lights; sees flashes of light; sees "curtains" over eyes NONE OF ABOVE	
3	VISUAL APPLIANCES	Glasses; contact lenses; lens implant; magnifying glass 0. No 1. Yes	

sight, encouragement, or cueing” in order to perform activities of daily living.

One of the 18 Resident Assessment Protocols is on dementia. The protocol provides additional information about dementia to help nursing home staff members assess the resident accurately and develop an appropriate care plan (309). Several other Resident Assessment Protocols address problems and care needs that are relevant for nursing home residents with dementia, including delirium, psychosocial problems, behavioral symptoms, activities, psychotropic drug use, and physical restraints.

Compared with other assessment instruments used in nursing homes in the past, the resident assessment system developed by the consortium, including the Minimum Data Set and the Resident Assessment Protocols, places much greater emphasis on assessment of residents' cognitive status and the problems and care needs that are common among nursing home residents with dementia. Although the existence of this resident assessment system does not guarantee that a resident's needs will be accurately identified or, once identified, that the needs will be met, the existence of the system certainly makes both outcomes more likely.

As of January 1992, all States were using the resident assessment system developed by the consortium (329). Eleven States had added some items to the Minimum Data Set.

State Licensing Regulations

Each State licenses nursing homes on the basis of State standards. Although nursing homes that choose not to participate in the Medicare and Medicaid programs are not subject to Federal Medicare and Medicaid regulations, all nursing homes are subject to State licensing regulations, including nursing homes that serve only private-pay residents (225,320).

State licensing regulations vary greatly. Some States have very complex, stringent, licensing regulations, whereas other States have simpler, less stringent regulations (94,225,318). In 1984, one-fourth of the States were using the Federal Medicaid regulations for State licensing purposes (318).

Administrative rulings and interpretations of State licensing regulations are common. These administrative rulings and interpretations become part of a

State's licensing regulations and generally add to their complexity.

Five States have changed their licensing regulations to add requirements for special care units, and one State has established requirements for special care units as an interpretation of the State's licensing requirements. These State regulations and requirements are discussed later in this chapter.

Federal Medicare and Medicaid regulations require that nursing homes have a State license (463). In effect, therefore, for a given State, the Federal regulations incorporate that State's licensing regulations. In the case of States whose requirements are more stringent or just different than the Federal requirements in some other way, these different and more stringent State requirements effectively become part of the Federal requirements.

State Certificate of Need Regulations

State certificate of need laws require explicit State approval before a nursing home can be built or expanded. As of 1988, 38 States had such laws (333). Certificate of need laws are intended to limit the supply of nursing home beds in a State. It is generally believed that any additional nursing home beds will eventually be filled with Medicaid-eligible residents and ultimately increase State expenditures for nursing home care (318). By controlling the bed supply, certificate of need laws are expected to limit these expenditures.

The process of obtaining a certificate of need is lengthy and complex in many States. Tables 6-2 and 6-3 in chapter 6 list the steps involved in obtaining a certificate of need in Massachusetts and New York. As discussed later in this chapter, at least six States have altered the process for obtaining a certificate of need so that applicants who propose to create special care units receive special consideration.

Other State and Local Government Regulations That Apply to Nursing Homes

Many State and local government regulations apply to nursing homes as well as other buildings, businesses, and health care facilities. These regulations include fire safety codes, zoning codes, building codes, and sanitation codes. Some of these regulations are incorporated into the requirements for obtaining a State license or a certificate of need.

Survey and Certification Procedures

Nursing homes are inspected regularly by individual surveyors or teams of surveyors who monitor the facilities' compliance with each of the types of regulations discussed thus far in this chapter. Although the regulations are clearly important in themselves, their impact depends on how they are interpreted and applied by the surveyors.

Inspection and certification of nursing homes is primarily a State function (149,225). Each State has at least one agency—often referred to as a survey and certification agency—that performs inspections for Medicare and Medicaid certification of nursing homes. This agency usually also performs inspections for State licensing purposes, but other State and local agencies are involved in these inspections as well. Health building inspectors, fire marshals, and sanitarians inspect nursing homes in connection with certification requirements, licensing requirements, and other State and local government regulations that apply to nursing homes. The Department of Veterans Affairs (VA) also inspects all VA and nonVA nursing homes in which it places veterans (289).

The resources allocated by State and local governments to nursing home inspections vary. A 1989 survey of State agencies that perform inspections for Medicaid certification and/or State licensing found that 5 States had fewer than one surveyor for every 10 nursing homes, whereas 5 States had 3 or more surveyors for every 10 nursing homes (149).

OBRA-87 mandated changes in the survey and certification procedures for Medicare and Medicaid certification of nursing homes. Coupled with the new requirements for Medicare and Medicaid certification, the survey procedures mandated by OBRA-87 are intended to focus more on residents and the outcomes of care than on written policies, staff credentials, physical design features, and other factors that may affect a facility's capacity to provide care (309,462,456). The new survey procedures are also intended to allow survey agencies to concentrate their attention on nursing homes that provide substandard care (456). OBRA-87 requires that each nursing home receive an unannounced "standard survey" annually. Facilities that are found in the standard survey to provide substandard care must receive an "extended survey" within 2 weeks. The extended survey is intended to identify

the facility's policies and procedures that resulted in the substandard care.

OBRA-87 makes States responsible for the standard and extended surveys (320,456). Annually, the Federal Government is required to conduct validation surveys of at least 5 percent of the nursing homes surveyed by each State in order to determine the adequacy of the State survey. The Federal Government is also required to inspect State-owned nursing homes.

OBRA-87 requires that surveys for Medicare and Medicaid certification of nursing homes be conducted by a multidisciplinary team, including a registered nurse (320). Members of the survey team must meet minimum Federal qualifications, including completion of a federally approved training and testing program. OBRA-87 also requires that State survey and certification agencies employ sufficient staff to investigate complaints and to monitor facilities that do not meet the requirements or are in danger of falling out of compliance (320).

One purpose of the new survey procedures is to reduce the inconsistency of survey procedures in different States and localities (320). OBRA-87 requires that the standard and extended surveys use a survey instrument developed, tested, and validated by the Federal Government. The surveyor training requirements mentioned above are also intended to reduce the inconsistency in survey procedures.

In September 1989, HCFA issued interpretive guidelines to help surveyors apply the new requirements for Medicare and Medicaid certification of nursing homes (320). The guidelines were revised following the release in September 1991 of the final requirements for Medicare and Medicaid certification of nursing homes. In late 1991, HCFA sent the revised guidelines out for review. The guidelines prescribe methods to be used in conducting inspections, including procedures for interviewing residents and reviewing resident assessments and care plans.

State Long-Term Care Ombudsman Programs

The Older Americans Act mandates that every State have a Long-Term Care Ombudsman Program to investigate and resolve complaints of residents of nursing homes and other residential care facilities. The State programs vary, but most States use both paid and volunteer staff and have offices at both the

State and local level. In 1990, State ombudsman programs had an average of one paid staff member at the State or local level for every 3200 nursing home beds; the range in different States was from one paid staff member for every 789 beds to one paid staff member for every 21,500 beds (321). Total spending for State Long-Term Care Ombudsman Programs averaged \$11.15 per nursing home bed per year and ranged from \$2.09 to \$68.05 per bed per year in different States.

Ombudsmen have the authority to enter a nursing home at any time to investigate a complaint or advocate for an individual resident (320). They can also visit nursing homes to become acquainted with the residents, monitor their care generally, and inform them of their rights. A 1990 survey of long-term care ombudsmen found that only 16 percent reported visiting the nursing homes in their jurisdiction more than once a month for any of these purposes (321).

OBRA-87 created a new role for State Long-Term Care Ombudsman Programs in connection with the survey process for Medicare and Medicaid certification of nursing homes. The law requires the survey and certification agency to contact the Long-Term Care Ombudsman Program to inquire about complaints the ombudsman program may have received about a facility that is being surveyed (320). The survey and certification agency is required to invite the ombudsman to attend the exit conference at the end of a facility's survey when the survey findings are discussed. Lastly, the survey and certification agency is required to inform the ombudsman if the facility is not in compliance with any of the certification requirements.

Summary and Implications

The existing regulatory structure for nursing homes is extremely complex, and many aspects of the structure are in flux now because of OBRA-mandated changes in the Federal regulations for Medicare and Medicaid certification of nursing homes and the survey and certification procedures associated with those regulations. The OBRA-mandated changes are likely to improve the care received by nursing home residents with dementia. The resident assessment system developed to implement OBRA-87 focuses much more than assessment instruments used previously in nursing homes on the residents' cognitive status. The assessment system

emphasizes the care needs that are common among nursing home residents with dementia, and OBRA regulations require that services be provided to meet those needs.

Two factors could limit the benefits of OBRA-related changes for individuals with dementia. One obvious factor is a failure to implement the changes. Such a failure could occur as the result of a lack of leadership and political will at the Federal, State, or local level. It could also occur as a result of insufficient government funding to implement the changes, including insufficient Medicare and Medicaid reimbursement for nursing home care, insufficient funding for nurse aide training, and insufficient funding for survey and certification staff and surveyor training. Some of this funding comes from the Federal Government, but some comes from States, so finding problems that affect implementation of OBRA are likely to vary from State to State.

The second factor that could limit the benefits of OBRA-related changes for individuals with dementia is lack of knowledge among nursing home administrators and staff members and nursing home surveyors about the implications of the new requirements for residents with dementia. With respect to the OBRA-87 requirements cited earlier in this chapter, these individuals might ask, for example: what constitutes good quality of life for a resident with dementia; what constitutes unavoidable diminution in the resident's ability to perform activities of daily living; what activities meet the interests and needs of nursing home residents with dementia; what rehabilitative services are needed by nursing home residents with dementia; what is a safe, home-like environment, and what are comfortable levels of sound, lighting, and temperature? Research-based answers to these and other similar questions do not exist at present, and certain of the questions are not amenable to research. There is also disagreement among clinicians about the answers. Yet answers are needed for effective implementation of the new requirements.

STATE REGULATIONS AND OTHER STATE POLICIES FOR SPECIAL CARE UNITS

As of early 1992, six States had special regulations for special care units. At least five additional States were developing regulations, and other States were considering doing so. One State had guidelines

for special care units instead of regulations, and one other State was in the process of developing guidelines. Other policies for special care units that have been implemented by a few States include altering the process for obtaining a certificate of need so that applicants who propose to establish special care units receive special consideration, funding individual special care units, and funding research on special care units. This section discusses these State regulations and policies.

Some of the State regulations and policies for special care units have been mandated by State legislatures, and others have been put in place by executive decision. The initiative for the regulations and other policies has usually come from State officials and/or State Alzheimer's disease task forces, but these individuals and groups were often responding to concerns raised originally by family members, special care unit operators, and nursing home surveyors.

The regulations and policies differ in their primary intent. Some are intended primarily to assure that special care units are not established and operated solely for marketing purposes and do, in fact, provide something special for their residents. Other regulations and policies are primarily intended to protect the rights of special care unit residents, particularly those in locked units. Still other regulations and policies are intended to promote the establishment or evaluation of special care units.

Some industry representatives believe that States establish regulations for special care units in part to raise State revenues (337). States generally charge nursing homes fees in connection with new construction or extensive remodeling. Consequently, special care unit regulations that include physical design requirements are likely to generate fee-based income for the State.

Six States' Regulations for Special Care Units

Six States—Iowa, Texas, Colorado, Washington, Tennessee, and Kansas, have special regulations for special care units. Iowa created a new licensing category for special care units, and Texas created a voluntary certification program. Colorado, Washington, and Tennessee added requirements for special care units to their general licensing requirements for all nursing homes, and Kansas added an interpre-

tation on special care units to its licensing requirements for all nursing homes.

The regulations developed by these six States are presented in some detail in this section. OTA's intent in presenting these regulations in detail is to call attention to their diversity and some of the particular features they require.

Iowa's Regulations for Special Care Units

Iowa is the only State that currently requires special care units to have a special license in addition to the license all nursing homes must have. The requirements for the special license were developed in 1988 by a task force appointed by the Iowa Department of Inspections and Appeals. The department's intent in creating a special license was to assure that special care units provide appropriate care for their residents and are not established only for marketing purposes (334). When first implemented in November 1988, the special license was voluntary in the sense that nursing homes had to obtain a license for a special care unit only if they were going to advertise they had such a unit. In the first year, one nursing home applied for a special license.

At the urging of the State's Task Force on Alzheimer's Disease and Related Disorders, the licensing requirements were made mandatory, effective in July 1990. Now, nursing homes must have a special license if they are caring for individuals with dementia in a distinct part of the facility, with a separate staff, and if they care only for individuals with dementia in that part of the facility (334). The license, which was first referred to as a license for "special units for people with Alzheimer's disease or related disorders," is now referred to as a license for "chronic confusion or dementing illness units or facilities." This change is intended to preclude facilities from arguing that they do not have to obtain a special license because their residents do not have a diagnosis of Alzheimer's disease. As of July 1991, 17 nursing homes had obtained a special license, and 2 more facilities had applied but not yet been approved for a license.

To obtain a special license, the Iowa regulations require a unit to have:

- . a statement of philosophy, with objectives stated in terms of outcomes,

- admission and discharge policies, including a policy requiring a physician's approval for a resident's admission to the unit,
- an interdisciplinary care planning team,
- safety policies that specify a method of locking or otherwise securing the unit and steps to be taken if a resident is missing from the unit,
- policies that explain the programs and services offered in the unit,
- policies that describe the numbers, types, and qualifications of the unit staff,
- policies that assure residents' right to have visitors,
- quality assurance policies,
- preadmission assessment of residents,
- staff training, including at least 6 hours of training for all new staff on nine topics listed in the regulations and 6 hours of inservice training annually for all staff,
- 2 hours of nursing staff time per resident per day, and a staff member on the unit at all times (Iowa Administrative Code, Sections 10A.104(5) and 135c.14).

In October 1990, several physical design specifications were added to the Iowa regulations. They require a special care unit to have:

- . a design such that residents, staff, and visitors do not pass through the unit to reach other parts of the facility,
- . a locking system that meets the Life Safety Code and is approved by the fire marshal or an alternate system for securing the unit,
- . a secure outdoor area with nontoxic plants,
- . no steps or slopes,
- . a separate dining area used only for unit residents,
- . a private area for nurses to prepare resident records,
- . a unisex toilet room that is visible from the lounge and activity area, and
- . a design that minimizes breakable objects (Iowa Administrative Code, Section 61.13).

Iowa is enforcing the licensing regulations, and several nursing homes have closed their special care unit because the unit did not meet the licensing requirements (169). When officials of the Iowa Department of Inspections and Appeals become aware of a unit that is not licensed, they do not charge the facility with a violation of the regulations, but they do visit the unit to determine whether it is

a special care unit within the regulatory definition, and if it is, they notify the facility that a special license is required (334).

The administrator of one nursing home in Iowa that has had a special care unit for 5 years told OTA that although the unit is providing good care for its residents, it does not meet the licensing requirements (452). She believes some of the State's requirements, particularly the physical design specifications added in 1990, are overly rigid and require features that are not necessary for good care of residents with dementia.

Texas' Regulations for Special Care Units

Texas has a voluntary certification program for special care units that was mandated by the State legislature in 1987 and became effective in February 1988. Like the early phase of Iowa's licensing program, nursing homes in Texas only have to obtain a license for a special care unit if they are going to advertise that they have such a unit. The creation of the voluntary certification program was intended to encourage the establishment of special care units. As of September 1991, however, only 8 special care units had been certified, even though the Department of Health is aware of at least 60 nursing homes in the State that have a special care unit (1 12).

To be certified, the Texas regulations require a unit to have:

- safety measures to prevent residents from harming themselves or leaving the unit without supervision,
- policies to prevent residents from abusing the property and rights of other residents,
- staff training, including at least 8 hours of training for all new staff on five topics listed in the regulations and 4 hours of inservice training annually for all staff,
- specified staff-to-resident ratios for each shift,
- staff who are assigned exclusively to the unit,
- a social worker to assess the residents on admission, conduct family support group meetings, and identify and arrange for the use of community resources,
- a specified amount of space per resident in public areas, including the dining area,
- a specified number of showers, bathtubs, toilets, and lavatories per resident,
- a nurses' station with a place to write, a chair, "task illumination, ' a telephone or intercom to

the main staff station, and a place to store resident records,

- activity and recreational programs tailored to the individual resident's needs,
- resident access to a secure outdoor area with no toxic plants,
- admission practices that limit admission to individuals with a diagnosis of Alzheimer's disease or a related dementing disorder whose attending physician has documented the reasons for the individual's admission to the unit,
- patient care practices that provide for residents' privacy during treatment and personal care,
- patient care practices that provide for careful, time-limited use of restraints and psychotropic medications,
- at least two exits,
- latches or other fastening devices for the exit doors that are easy to release, even in the dark, and
- if the exit doors are locked, the facility must have a complete sprinkler system or fire alarm system; the locks must release automatically if the sprinkler or alarm system is activated or if there is a power failure; and there may be a keypad or buttons at the door for routine use by the staff (Texas Department of Health, Chapter 145, Subchapter B, 145.301-145.304).

At public hearings in October 1989, witnesses made both positive and negative comments about Texas' voluntary certification program (443). The positive comments focused on the importance of the training requirements and the value of the certification program in providing initial guidelines for facilities and preventing facilities from advertising a special care unit that does not meet minimum standards. The negative comments focused on the difficulty of setting standards in a changing field and the need for revisions to the standards that would require higher staff levels during some periods of the day, documentation of staff training, and programs and policies to address the needs of family members. Officials of two companies that have several nursing homes with special care units in Texas told OTA that the companies consider the State's requirements for voluntary certification difficult to meet and costly; that some of the companies' facilities are certified and others are not; and that the companies do not believe their certified facilities are providing better care than their uncertified facilities (3,141).

Colorado's Regulations for Special Care Units

Colorado has special requirements for "secure units" which apply to locked special care units as well as any other locked nursing home units. The requirements were developed in 1985-1986 by the Colorado Department of Health. Their primary intent is to protect individuals who are placed in locked units (409). The requirements are incorporated in the State's regulations for all nursing homes, and no special license or certification is required for the units.

The Colorado regulations require a 'secure unit' to have:

- an admissions evaluation team with specified members, including a person with mental health or social work training who is not a member of the nursing home staff,
- admission practices to ensure that individuals are not placed on the unit unless the evaluation team finds that: 1) they are dangerous to themselves or others, or 2) they habitually wander and would not be able to find their way back, or 3) they have significant behavioral problems that seriously disrupt the rights of other residents, and 4) less restrictive alternatives have been unsuccessful in preventing harm to themselves or others, and 5) legal authority for the restrictive placement has been established,
- admission practices to ensure that individuals are not placed on the unit for punishment or the convenience of staff and that the unit is the least restrictive alternative available,
- admission practices to ensure that those placed on the unit because they are dangerous to themselves or wander habitually are protected from residents who are dangerous to others or whose behavior disrupts the rights of others,
- documentation of the reasons for residents' admission to the unit and a physician's approval of the admission,
- written programs to treat the residents it admits,
- practices to allow visitors,
- sufficient staff to provide for the needs of the residents,
- staff who are experienced and trained in the needs and care of the types of residents in the unit,
- additional social work and activities staff to meet the social, emotional, and recreational

needs of residents and the social and emotional needs of residents' families in coping with the residents' illness,

- social services and activities that allow regular interaction with non-confused residents of the facility and the outside community,
- a provision that residents may not be locked into or out of their rooms,
- a specified amount of space per resident in public areas,
- a secure outdoor area, *if the facility has an outdoor area for residents of other units,*
- practices that meet the fire safety standards of the 1985 Life Safety Code, and
- periodic reevaluation of the residents' placement (Colorado regulations for Long-Term Care Facilities, sections 19.1-19.9).

The Colorado regulations specify that residents with Alzheimer's disease whose condition has stabilized may remain on the unit if the evaluation team concludes the "placement is necessary to avoid a likely recurrence of the condition that was the purpose of the initial placement on the unit" (Colorado Regulations for Long-Term Care Facilities, section 19.5.3).

Washington's Regulations for Special Care Units

Washington State has special requirements for "protective units for cognitively impaired residents." One set of requirements was implemented in 1986 as an interpretation of the State's licensing requirements for all nursing homes (500). In 1989, the interpretation was replaced by a new set of requirements that are incorporated in the State's regulations for all nursing homes. No special license is required for the units.

As of late 1991, Washington State was reviewing all its nursing home regulations, including the requirements for "protective units for cognitively impaired residents" (179). Changes in the requirements are a possibility.

The Washington State regulations require a "protective unit for cognitively impaired residents" to have:

- a dining area that may also serve as a day room for the unit,
- a secure outdoor area with 1) walls or fences of a specified height, 2) an ambulation area with firm stable surfaces that are slip-resistant, 3) exits that release automatically if the fire alarm

is activated, 4) outdoor furniture, and 5) non-toxic plants,

- a staff toilet room,
- corridors no less than 10 feet wide in new construction and 8 feet wide in renovated units,
- floors, walls, and ceiling surfaces of contrasting colors; the surfaces may conceal areas the residents should not enter,
- door thresholds that are one-half inch high or less,
- an electrical signaling system in each room for staff use in an emergency,
- no keyed locks on the exit doors or any door between a resident and the exit; exits may be secured by alarms or doors which require cognitive ability to open or by other methods that open automatically if the fire alarm is activated; the releasing devices for the doors must be labeled with directions, accessible by residents, and approved for use by the State fire marshal, and
- no use of a public address system except for emergencies (Washington Administrative Code 248-14-211).

Tennessee's Regulations for Special Care Units

Tennessee has special requirements for "special care units for ambulatory patients with Alzheimer's disease and related disorders." The regulations were developed on the initiative of the Governor's Task Force on Alzheimer's Disease and went into effect in March 1991. Nursing homes with a special care unit must apply to the State's Board for Licensing Health Care Facilities to have the unit "designated" as a special care unit. To avoid delays in opening new special care units, nursing homes that are in compliance with the State's general nursing home requirements may open a special care unit without waiting for the Board to designate the unit (36). Eventually, however, all special care units must be designated by the board.

As of June 1992, 12 special care units had been designated by the board, and one additional nursing home had applied for designation of its special care unit (36). Thus far, no nursing home that has applied for designation for a special care unit has been turned down.

The Tennessee regulations require a "special care unit for ambulatory patients with Alzheimer's disease and related disorders" to have:

- admission practices such that each resident has a diagnosis made by a physician that identifies the specific cause of the resident's dementia and each resident's need for admission to the unit is determined by an interdisciplinary team that includes a physician who is experienced in managing individuals with dementia, a social worker, a nurse, and a relative or other advocate for the resident,
- access to a protected outdoor area,
- separate dining/activity areas,
- a stated bed capacity that is not exceeded at any time,
- a design such that visitors and staff do not pass through the unit to reach other parts of the nursing home,
- 3.5 hours of direct care per resident per day, including .75 hours of direct care provided by a licensed nurse,
- resident care plans that are developed, periodically reviewed, and implemented by an interdisciplinary team that includes a physician who is experienced in managing individuals with dementia, a social worker, a nurse, and a relative or other advocate for the resident,
- a 40-hour classroom training program for nurse aides that is in addition to the 40-hour basic training program for all nurse aides and covers the causes, progression, and management of dementia, including methods of responding to residents' behavioral symptoms, alleviating safety risks, assisting residents with activities of daily living, and communicating with residents' families.
- procedures for identifying and alleviating job-related staff stress,
- a family support group that meets at least quarterly, provides family education and support, and allows for family input into the operation of the unit, and
- if the unit is locked, 'extraordinary and acceptable fire safety features and polices' to protect the residents (Tennessee State Rule 1200-8-6-.10)

The original intent of the Governor's Task Force in initiating the special care unit regulations was that Medicaid reimbursement would be increased for special care units that met the specified requirements, but this objective has not been realized. Like all other States, Tennessee provides no higher reimbursement for Medicaid-eligible individuals in

special care units than in any other nursing home unit. In the first year after the regulations went into effect, the Board for Licensing Health Care Facilities received many inquiries about the designation of special care units but relatively few applications. The board's director believes this is because the current level of reimbursement for Medicaid-eligible individuals does not cover the additional cost a nursing home would incur to comply with the special care unit requirements.

Kansas' Regulations for Special Care Units

Kansas has requirements for special care units that were issued in 1989 as an interpretation of the State's licensing regulations for all nursing homes. As of September 1991, the Kansas Adult Care Home Program was in the process of revising the licensing regulations and had proposed that the interpretation on special care units be included as a requirement in the revised regulations (267).

The Kansas interpretation requires a special care unit to have:

- admission criteria, including a requirement that the resident have a medical diagnosis and a physician's order to be admitted,
- a staff training program and documentation that staff members have completed the program,
- a staff member on the unit at all times;
- a nurses' sub-station located so that the corridors are visible from the sub-station,
- nurse-call signals that are visible and audible from the corridors and nurses' sub-station,
- living, dining, activity, and recreational areas that are accessible to the residents,
- resident care plans that identify the problems that justify the resident's placement on the unit and identify interventions that could correct or compensate for those problems,
- methods of securing the unit that are the least restrictive possible and comply with all life safety codes (Kansas Administrative Rules, 28-39-78 (a) (6) and (7) and 28-39-87 (c) and (e)).

Kansas is enforcing these requirements. At the beginning of a nursing home inspection, the surveyor asks whether the facility has a special care unit and then evaluates the identified unit, if any, on the basis of the requirements of the interpretation in addition to the general requirements for all nursing homes (267). No information is available about the

number of special care units identified in this way by the surveyors. The director of the State's Adult Care Home Program told OTA that special care units are most likely to have trouble with three of the requirements: 1) the admission criteria, 2) the staff training, and 3) the resident care plan (267).

States That Are Developing or Considering Developing Regulations for Special Care Units

State legislatures in four States have mandated the development of special regulations for special care units. Two State health departments are developing regulations for special care units without a prior legislative mandate, and one State health department is considering doing so. State Alzheimer's disease task forces and other legislatively appointed bodies in several States have recommended the development of regulations for special care units, and in one State, the legislature has mandated the appointment of a committee to determine whether regulations are needed.

In 1989, the Arkansas legislature passed a bill requiring the Department of Human Services to establish a mandatory certification program for special care units. In 1990, after considering the issue of regulations for special care units and with the approval of the bill's legislative sponsor, the department decided not to go ahead with the certification program (147). As of early 1992, however, the State was reconsidering this issue. One possibility being considered was the creation of a new licensing category for special care units.

In 1989, the Nebraska legislature passed a resolution mandating a study of special care unit standards that would result in recommendations for legislation to regulate the units (323). In response, the Governor's Alzheimer's Disease Task Force formed a subcommittee to examine this issue and make recommendations. The subcommittee's report, released in November 1989, specifies principles, goals, and objectives for special care units, a list of recommended policies and procedures that are very similar to Iowa's requirements for a special care unit license, and a proposed training program for special care unit staff members. The subcommittee recommended that the Nebraska Department of Health develop regulations based on the content of this report and the Iowa licensing requirements. The subcommittee concluded that required staffing ratios for special care units should be based on 'acuity

ratings of the patients" and that Medicaid reimbursement for residents of special care units should also be based on "acuity ratings" and on the cost to the nursing home of complying with the State requirements for special care units, once developed (323). As of September 1991, the Department of Health was still working on draft regulations (447).

In 1991, the Oregon legislature passed a bill requiring nursing homes and residential care facilities that have a special care unit to register with a State agency, the Senior and Disabled Services Division, by Oct. 1, 1991 (335). Twenty-four facilities registered by that date, including 20 nursing homes and 4 residential care facilities (126). The Oregon legislation also requires that by June 1, 1993, facilities with a special care unit must have a special "endorsement" on their general license. To obtain the endorsement, the special care units will have to meet requirements in three areas: "1) care planning, including physical design, staffing, staff training, safety, egress control, individual care planning, admission policy, family involvement, therapeutic activities, and social services; 2) continuity of basic care requirements; and 3) marketing and advertising of the availability of and services from Alzheimer's care units" (335). As of early 1992, the Senior and Disabled Services Division was developing the requirements for the endorsement. An advisory committee that includes three Alzheimer's advocates, three industry representatives, and one official of an area agency on aging had been appointed to assist the division in developing the requirements (126).

In 1991, the North Carolina legislature passed a bill requiring the State Medical Care Commission to develop standards for special care units in nursing homes and requiring the State Social Services Commission to develop standards for special care units in residential care facilities. Both sets of standards are to address "the type of care provided in a special care unit, the type of resident who can be served on the unit, the ratio of residents to staff members, and the requirements for the training of staff members" (33 1). As of early 1992, both sets of standards had been drafted and were in the approval process (71). As a part of that process, the State legislature asked for a cost impact statement to determine the cost implications of the standards.

The New Jersey Department of Health is developing regulations for special care units (161). The

regulations will require special care units to meet 65 percent of the requirements if they are going to advertise as a special care unit.

The Oklahoma Department of Health is also developing regulations for special care units, primarily in response to recommendations of the State Task Force on Alzheimer's Disease and Related Disorders (326). The regulations will require special care units to have a special license in addition to the license all nursing homes must have.

The New Mexico Department of Health is considering the development of regulations for special care units (499). The department intends to work with the Alzheimer's Association and the School of Nursing at the University of New Mexico on this project.

In the past few years, State Alzheimer's disease task forces in at least two additional States—Arizona, and Indiana—have recommended the development of regulations for special care units (14,65,203). In its 1989 report, the Arizona Advisory Committee on Alzheimer's Disease and Related Disorders cited complaints from many families about 'difficult and stressful encounters with poorly run homes' and about the lack of standards and regulatory guidance in the selection of residential care homes (14). The committee recommended that the Arizona Department of Health Services be authorized "to develop guidelines, set standards, and regulate specific Alzheimer's patient care units in nursing homes that are presented to the public as providing specialized care" (14). Following the release of its 1989 report, the committee developed draft standards. As of early 1992, the State had not yet agreed to enforce the standards, and the committee was seeking ways to obtain voluntary compliance (432).

In Indiana, the State's Family and Social Services Administration contracted with the Alzheimer's Association of Greater Indianapolis to develop standards for special care units and to make a recommendation about whether the State should institute either a voluntary or a mandatory certification program for special care units (428). The contract ran from January 1992 to June 1992. Although the standards proposed by the Alzheimer's Association may eventually be the basis for regulation, the State has not yet committed itself to establishing regulations.

In California, some members of the State's Alzheimer's Advisory Committee drafted guidelines for special care units but concluded that it would take several years to get the guidelines incorporated into the State's nursing home regulations with or without legislation (484). As a result, the committee is working with California's nursing home associations and individual nursing home operators toward eventual voluntary implementation of the guidelines. As of July 1992 the draft guidelines were being reviewed by the associations, consumers, policymakers, and others (255).

In Rhode Island, in early 1992, the Long-Term Care Coordinating Committee, a legislatively appointed body, approved draft legislation to create standards for special care units (284). The draft legislation has been sent to the State legislature.

Lastly, in Virginia, in March 1992, the State legislature passed a resolution requiring the establishment of a committee to determine whether the State should have regulations for special care units. The Virginia Department of Mental Health has appointed the committee.

States That Have Developed or Are Developing Guidelines for Special Care Units or for the Care of People With Dementia in All Nursing Homes

New Hampshire has guidelines for special care units, and Missouri is developing such guidelines. The New Hampshire guidelines are published in an 8-page booklet that has one section for families who are trying to evaluate special care units and another section for nursing home operators who are interested in establishing a special care unit (325). By providing information for families and nursing home operators in the same publication, the New Hampshire booklet directs the attention of the nursing home operators to what families are likely to be looking for in a special care unit.

The New Hampshire State agency that produced the booklet chose to publish guidelines rather than regulations because of an awareness of the diversity of opinions about special care units both inside and outside the State government (216). The agency has not ruled out the possibility of developing regulations in the future.

In 1990, the Missouri Division of Aging appointed a special care unit committee to develop

guidelines (153). One reason Missouri chose to develop guidelines rather than regulations was a belief in the State that nursing homes would expect regulations to be accompanied by increased reimbursement for special care units and that the development of guidelines would not create that expectation.

Massachusetts took a different approach than other States in its "Guidelines for Care of Patients With Alzheimer's Disease and Related Disorders in Massachusetts Long-Term Care Facilities." These guidelines, published in 1988, pertain to the care of individuals with dementia in any nursing home unit (288). As of late 1991, a new set of guidelines for the care of individuals with dementia in nonspecialized nursing home units was being reviewed (362). At the same time, the Eastern Massachusetts Chapter of the Alzheimer's Association, in cooperation with the Massachusetts Department of Health, was drafting a separate set of guidelines for the care of individuals with dementia in special care units.

In its 1991 report, the Maryland Coordinating Council on Alzheimer's Disease and Related Disorders recommended an approach similar to the 1988 Massachusetts guidelines (286). The Council recommended that the State work with industry and advocacy groups to develop guidelines that would apply to the care of individuals with dementia in any nursing home unit. The Council also recommended that the State collect information about special care units. It recommended against the development of regulations, saying, "States and advocacy groups which have attempted to develop regulations or detailed guidelines for special care units have not been particularly successful" (286).

States That Have Certificate of Need Exceptions for Special Care Units

As noted earlier, certificate of need laws are intended to limit the supply of nursing home beds in a State. At least six States--Georgia, Kentucky, Michigan, Mississippi, New Jersey, and Ohio--have altered the process for obtaining a certificate of need, either on an ongoing or a one-time basis, so that applicants who propose to create special care units or special nursing homes for people with dementia receive special consideration. To OTA's knowledge, only two of these States, Kentucky and Michigan, have special requirements for the units or facilities developed with a certificate of need excep-

tion (35,155,161,172). This lack of requirements created consternation in at least one of the other States when State surveyors were preparing for their annual inspection of a facility that had created a special care unit with a certificate of need exception, and the surveyors wanted to know what to look for when they inspected the unit (155).

In Kentucky, the legislature created a time-limited exception to the State's certificate of need law to allow the establishment of "free-standing facilities limited to the care of patients with Alzheimer's or related disorders" (172). The facilities had to be approved by July 1991 and have to meet special licensing requirements. Interestingly, the licensing requirements for free-standing Alzheimer's facilities do not apply to special care units, and free-standing Alzheimer's facilities do not have to meet the State's regulatory requirements for all nursing homes. As of the cutoff time in July 1991, one facility had obtained a license, and another facility was in the process of doing so (343).

Effective in 1989, the Michigan Certificate of Need Commission set aside 200 beds from the total number of allowable new nursing home beds in the State to be used for special care units. The Commission determined that special care units created through this certificate of need exception must:

- admit only patients who require long-term care and have been appropriately classified as having a score below a given level on the Global Deterioration Scale, a widely used assessment instrument,
- participate in the State Alzheimer's registry,
- operate for a minimum of 5 years and conduct and participate in research programs approved by the department to evaluate the effectiveness of special care units and to study the relationship between the needs of Alzheimer's patients and the needs of other nursing home residents,
- be affiliated with a research facility or program,
- be attached or geographically adjacent to a licensed nursing home,
- have no more than 20 beds,
- have direct access to a secure indoor or outdoor area for unsupervised activity,
- have a separate dining room for use only by residents of the unit,
- have a physical environment designed to minimize noise and light reflections, and
- have trained staff (304).

As of March 1991, the first five applicants for certificate of need exceptions had been disapproved because they did not submit a research protocol or were not affiliated with a research program (514).

Other State Policies for Special Care Units

In addition to regulations, guidelines, and certificate of need exceptions, several States have provided funding for individual special care units or for training staff members in special care units. In 1987, Massachusetts initiated its "Alzheimer's Unit Pilot Program" which has provided funding for eight nursing homes to create special care units. Connecticut has provided funding for a 120-bed nursing home and research center devoted to the care of individuals with Alzheimer's disease. Florida has provided funding for a long-term care facility and research center for individuals with Alzheimer's disease. Each of these projects is intended to develop, demonstrate, and evaluate methods of specialized dementia care.¹

California has funded at least two studies of special care units. One study compared two nursing home special care units, two nonspecialized nursing home units, and two specialized programs for individuals with dementia in board and care facilities (256). The results of this study are discussed in chapter 3. A second study is comparing various methods of preventing individuals with dementia from wandering away from a care setting. The study is evaluating the effectiveness of door alarms and wrist bands vs. a locked perimeter in achieving this purpose (484).

Beginning in 1991, Michigan has provided funding to the Alzheimer's Care and Training Center, a special care unit in Ann Arbor, Michigan, to support research on the care of individuals with dementia and to provide training about dementia for staff of the State's community mental health centers (384). Rhode Island has provided funding for the past six years for a training program that has been instrumental in establishing several special care units and specialized adult day centers (284).

Summary and Implications

Special care units are clearly an area of policy interest in many States. As discussed in the preceding sections, there are now:

- six States with regulations for special care units (IA, TX, CO, WA, TN, KS);
- five States in the process of developing regulations (NC, NE, NJ, OK, OR);
- one additional State that has passed legislation to mandate the development of regulations (AR);
- three additional States in which the State-appointed Alzheimer's task force or long-term care advisory council has recommended the development of regulations (AZ, IN, RI);
- one State that has passed legislation to establish a committee to study the need for regulations (VA);
- one State with guidelines for special care units (NH);
- one State that is developing guidelines for special care units (MO);
- one State with guidelines for the care of individuals with dementia in any nursing home unit (MA);
- one State in which the Alzheimer's task force has recommended the development of guidelines for the care of individuals with dementia that would apply to any nursing home unit (MD);
- six States that have altered the process for obtaining a certificate of need to encourage the establishment of special care units (GA, KY, MI, MS, NJ, OH); and
- six States that have provided funding for individual special care-units, for training in special care units, or for research on special care units (MA, CA, CT, FL, MI, RI).

These figures and the discussion in the preceding sections reflect information available to OTA as of early 1992. The figures indicate that a total of 28 States have, are in the process of developing, or are considering developing policies of some kind for special care units. (Five States are included twice in the list.)

¹ Several other States, e.g., Illinois and New York, have provided funding for nursing homes to develop improved methods of caring for residents with dementia in nonspecialized units. The New York Medicaid program pays an additional \$4 a day for residents with Alzheimer's disease in any nursing home (201). Maine and Oregon subsidize the care of some residents with dementia in specialized board and care facilities (303,501).

State policies for special care units are changing rapidly. Interest in the development of regulations for special care units is clearly growing. In some States, this interest is unopposed. In other States, such as Illinois, Michigan, Ohio, and Wisconsin, this issue is controversial, and some groups strongly oppose the development of regulations. Anecdotal evidence suggests that in a few States, regulatory proposals developed by Alzheimer's advocates have been opposed by other Alzheimer's advocates or nursing home industry representatives who have different ideas about whether there should be regulations, and if so, what the regulations should say.

Thus far, State policies for special care units have been developed without regard for the nursing home reform provisions of OBRA-87. Some of the State regulations for special care units were developed before OBRA-87 was passed, and many of the regulations were developed before the publication in February 1989 of the first version of the requirements to implement OBRA-87. It is surprising, however, that current discussion and debate about regulations and guidelines for special care units is proceeding with so little reference to the OBRA requirements. One exception to this observation is the 1991 report of the Maryland Coordinating Council on Alzheimer's Disease and Related Disorders. The report notes the likelihood that OBRA requirements will improve the care of people with dementia in nursing homes and stresses the importance for Alzheimer's advocates of monitoring facilities' compliance with the requirements (286).

Regulations for special care units now in effect in Iowa, Texas, Colorado, Washington, Tennessee, and Kansas have both similarities and differences. Each State's regulations address several common areas, e.g., admission criteria, security, staff training, and some aspects of physical design, but their requirements in each of these areas differ. Moreover, each State's regulations include requirements for features not addressed in other States' special regulations, e.g., Iowa's requirement that the unit and its outdoor area have no steps or slopes, Washington's requirement that floors, walls, and ceilings have surfaces of contrasting colors, and Colorado's requirement that residents may not be locked into or out of their rooms.

What is and is not included in these regulations is significant because of the implication that features

required by the regulations are particularly important in the care of nursing home residents with dementia and that other features not addressed by the regulations are not particularly important for these residents. The inclusion of certain features suggests that nursing home resources should be expended for those features and not others.

Many of the requirements for special care units in the six States probably are not more important in the care of nursing home residents with dementia than other nursing home residents, e.g., an interdisciplinary care planning team (IA, TN); policies that explain the programs and services offered in the unit (IA); a social worker to assess residents on admission, conduct family support group meetings, and identify and arrange for the use of community resources (TX); activity and recreational programs tailored to individual residents' needs (TX); a staff member on the unit at all times (KS); and nurse-call signals that are visible and audible from the corridors and the nurses' sub-station (KS).

Some of the requirements in the six States' regulations duplicate provisions of OBRA-87 that apply to all nursing home residents. For example, Iowa and Colorado require that special care units have policies to allow residents to have visitors. The OBRA requirement states, "The resident has the right and the facility must provide immediate access to any resident. . . subject to the resident's right to deny or withdraw consent at any time, by immediate family or other relatives of the residents. . . and by others who are visiting with the consent of the resident" (463).

In general, the six States' requirements focus more on staff training and physical design features and less on activity programs and programs to involve and support residents' families. Although there is no evidence from research that any one of these features is more likely than the others to produce positive outcomes, some dementia experts would probably favor a greater emphasis on activity programs and family support programs than exists in the six States' requirements.

Notably absent from the requirements of five of the six States is any mention of the role of physicians, except in approving residents' admission to the unit. Likewise, except for the Colorado regulations, mental health expertise and training are not mentioned, and their inclusion in the Colorado regulations may simply reflect the fact that these

regulations pertain to locked units for psychiatric patients as well as locked units for individuals with dementia. Requirements for ongoing physicians' involvement with residents appear in other sections of the States' nursing home regulations and in the Federal regulations for Medicare and Medicaid certification of nursing homes, and there may also be requirements for involving individuals with mental health training in other sections of the States nursing home regulations. Omission of these features in the special care unit requirements suggests, nevertheless, that they are less important in the care of nursing home residents with dementia than the features that are included.

The overall impact of State regulations on the growth of special care units is unclear. Anecdotal evidence suggests that some of the six States' regulatory requirements may discourage the growth of special care units, primarily because of the cost of complying with the requirements. The Hillhaven Corp. estimates that complying with Washington State's requirements increased the remodeling cost for a special care unit that opened in one of their facilities in 1991, from \$69,000 to \$118,000 (261). As a result, the corporation canceled plans for a special care unit in another facility in the State.

In considering the impact of State regulations on the growth of special care units, it is interesting to note that despite the growing number of special care units in the United States and the growing interest in regulations for special care units in many States, as of early 1992, there were fewer than 60 special care units nationwide that were specially licensed, certified, designated, or registered (17 to 19 units in Iowa, 8 units in Texas, 12 units in Tennessee, and 20 units in Oregon). OTA is not aware of any research that compares these licensed, certified, designated, or registered units to other special care units.

SPECIAL CARE UNIT GUIDELINES DEVELOPED BY OTHER PUBLIC AND PRIVATE ORGANIZATIONS

In addition to States, several other public and private organizations have developed or are in the process of developing guidelines for special care

units. Six of these organizations—the Alzheimer's Association, the American Association of Homes for the Aging, the Massachusetts Alzheimer's Disease Research Center, the National Institute on Aging's Alzheimer's Disease Education and Referral Center, the University of South Florida's Suncoast Gerontology Center, and the University of Wisconsin-Milwaukee's Center for Architecture and Urban Planning Research—have completed guideline documents. The Alzheimer's Association also has legislative principles for special care units. The Alzheimer's Society of Canada, the Alzheimer's Coalition of Connecticut, and the U.S. Department of Veterans Affairs are developing guidelines for special care units. Some multi-facility nursing home corporations have formal guidelines or standards for their special care units. Lastly, the Joint Commission on Accreditation of Healthcare Organizations, a private organization that offers voluntary accreditation for nursing homes, is developing guidelines to assist its surveyors in evaluating special care units in the nursing homes it accredits. This section briefly describes each of these guideline documents and efforts.

Some of the guidelines developed by these organizations are intended as a basis for government regulations, but most are not. None of the six completed guideline documents is intended as a basis for regulations. It is OTA's impression that obtaining agreement among experts in dementia care about the features that should be required in a special care unit is more difficult than some organizations anticipate. As a result, organizations that begin with the intention of developing standards that could be used for regulatory purposes sometimes conclude later on that there is insufficient agreement among experts to support such standards and decide to develop guidelines instead.

The American Association of Homes for the Aging—“Best Practices for Special Care Programs for Persons With Alzheimer's Disease or a Related Disorder”

In 1988, the Task Force on Alzheimer's Disease of the American Association of Homes for the Aging completed its 'Best Practices' document (10).² The document is intended to provide guidelines for exemplary special care programs and to help nursing

² To OTA's knowledge, the American Association of Homes for the Aging's "Best Practices" document has not been published. It is available from the Association however.

home operators and others distinguish specialized dementia care from standard practice. The document points out that, "although many of the best practices appear at first to be the standards of any quality program, when taken as a whole the best practices define what is special about dementia care" (10). It also emphasizes that little research has been conducted on specialized dementia care, that the "Best Practices" guidelines are based on clinical experience, and that with further experience and research, the guidelines will be validated, improved upon, and expanded. The document is not intended to be used for regulatory purposes.

The 22-page "Best Practices" document addresses seven areas: commitment, philosophy of care, therapeutic program, physical design, specialized staff, communications program, and education and research (10). For each of these areas, a general statement of the best practice is given; the characteristics or components of the best practice are listed; and the desirable outcomes in that area are described.

The Massachusetts Alzheimer's Disease Research Center—“Blueprint for a Specialized Alzheimer's Disease Nursing Home”

In 1989, with funding from the National Institute on Aging and the Administration on Aging, the Massachusetts Alzheimer's Disease Research Center held a 2-day workshop to develop a plan for a specialized Alzheimer's disease nursing home. The workshop participants tried to define what should be special about specialized care for individuals with dementia, what works for these patients, and which patients it works for. The resulting document, released in 1990, provides general conclusions and recommendations but emphasizes the need for rigorous research on specialized dementia care (287). It is not intended to be used for regulatory purposes.

The 20-page "Blueprint" document addresses three areas: policy planning, patient care programs, and architectural design (287). For each of these areas, a series of interrelated recommendations are made based on the workshop discussion and later review and revisions by the workshop participants.

The Alzheimer's Disease Education and Referral Center—“Standards for Care for Dementia Patients in Special Care Units”

In 1991, the Alzheimer's Disease Education and Referral Center completed its guidelines for special care units (6). The center, which is funded by the National Institute on Aging, is a clearinghouse for information about Alzheimer's disease for professionals, patients, families, and the general public. The "Standards" document is available to anyone who requests it. Despite its title, the document does not set standards. It discusses the pros and cons of developing standards for special care units, points out the lack of information about many aspects of specialized care for individuals with dementia, and emphasizes the need for research on the costs and effectiveness of special care units. The document is not intended to be used for regulatory purposes.

The 'Standards' document addresses seven areas: admission, environment, activities, staffing, training, expected impacts, and research issues (6). For each of these areas, a brief summary of current thinking is given.

The University of South Florida's Suncoast Gerontology Center—“Draft Guidelines for Dementia Specific Care Units (DSCUs) for Memory Impaired Older Adults”

In 1991, researchers from the Suncoast Gerontology Center published the findings of a study of 13 special care units in west central Florida (64). As discussed in chapter 3, the researchers used the study findings to create a typology of "minimally specific, moderately specific, and highly specific" units. On the basis of the study findings and the typology, the researchers developed guidelines for special care units (63). The guidelines are not intended to be used for regulatory purposes.

The 19-page "Draft Guidelines" document addresses ten areas: goals and philosophy, target population, admission and discharge criteria, resident assessment, physical environment, activity programs, unit size and staffing, staff training, family involvement, and ongoing evaluation (63). For each of these areas, a theoretical rationale and several specific guidelines are given.

***The University of Wisconsin-Milwaukee
Center for Architecture and Urban Planning
Research—“Environments for People With
Dementia: Design Guide”***

In 1987, the American Institute of Architects and the Association of Collegiate Schools of Architecture contracted with the Center for Architecture and Urban Planning Research at the University of Wisconsin-Milwaukee for a project to develop environmental design guidelines for special care units and other specialized settings for people with dementia. The project resulted in an annotated bibliography (363), a book of facility case studies (96), a regulatory analysis (94), and a design guide (95). The 97-page design guide discusses particular needs of persons with dementia, related therapeutic goals for the physical environment, and design principles for achieving those goals. It includes facility case examples and illustrations.

***The Alzheimer’s Association-Legislative
Principles and “Guidelines for Dignity”***

In 1988, the Alzheimer’s Association published a 13-page booklet to help families of individuals with dementia evaluate special care units (276). The booklet provides information about specialized dementia care and advises family members to visit a unit and to observe certain aspects of the physical environment, unit staffing, and resident care before deciding to place their relative with dementia in the unit.

As the number of special care units has increased, the association’s national office and many of its more than 200 chapters nationwide have received an increasing number of requests from family members and others for information and advice about special care units. Nursing home operators contact Alzheimer’s Association chapters for help in establishing a special care unit, and some chapters are providing formal or informal consultations to such facilities (114,231). State officials also contact the national office and the chapters for assistance in developing State relations for special care units. For these reasons, and because of concerns about special care units that are apparently established only for marketing purposes and provide nothing special for their residents, the association has developed legislative principles for special care units (4).

The association’s legislative principles are intended to direct legislators’ and regulators’ attention to the primary areas a State should include when drafting special care unit legislation or regulations. The 11 areas cited in the association’s principles are: 1) statement of mission, 2) involvement of family members, 3) plan of care, 4) therapeutic programs, 5) residents’ rights, 6) environment, 7) safety, 8) staffing patterns and training, 9) cost of care, 10) quality assurance, and 11) enforcement (4). The legislative principles recommend that States involve providers, consumers, ombudsmen, activities and occupational therapists, environmental design specialists, fire and safety officials, and licensure and survey officials in drafting specific standards in each of these areas.

In July 1992, the association released “Guidelines for Dignity: Goals of Specialized Alzheimer/Dementia Care in Residential Settings.” The 41-page “Guidelines” document discusses eight goals and guidelines for achieving the goals. The document is not intended to be used for regulatory purposes.

***The Alzheimer’s Society of Canada—
Forthcoming Guidelines***

In 1990, the Alzheimer’s Society of Canada, a private voluntary association, received a \$500,000 grant from the Canadian Government for a 3-year project to develop guidelines for the care of individuals with Alzheimer’s disease in a variety of settings, including special care units (7,313). In the first year of the grant, a literature review was conducted; Alzheimer’s Society staff members visited various care settings; and a questionnaire was sent out to 15,000 family caregivers. In 1991, draft guidelines were developed by the society’s staff with the assistance of an advisory committee (401). The guidelines, which were circulated for outside review in early 1992, address 11 areas: involvement in decisionmaking, assessment, staffing, programs and activities, training and education for caregivers, support for caregivers, physical and chemical restraints, preventing and responding to abuse, environmental design, and transportation. The society intends to publish two documents based on the guidelines—one document intended primarily for families and one intended primarily for government and provider agencies.

The Alzheimer's Coalition of Connecticut— Forthcoming Guidelines

The Alzheimer's Coalition of Connecticut, a private nonprofit organization that was formed after the expiration of the Governor's Task Force on Alzheimer's Disease, has developed a draft document that describes the important features of a special care unit. Although State officials have been involved in the development of the document, it is not intended as the basis for State regulations (512).

U.S. Department of Veterans Affairs— Forthcoming Guidelines

As discussed in chapter 3, a 1989 survey by the U.S. Department of Veterans Affairs (VA) identified special care units at 31 of the 172 VA medical centers nationwide. In 1991, the VA conducted site visits to 13 of the special care units and telephone interviews with staff of many of the other units. Partly on the basis of these site visits and interviews, the VA is developing guidelines for "Specialized Alzheimer's/Dementia Units" at VA medical centers (103). The guidelines describe three types of units—'diagnostic,' "behavioral management," and "long-term care' units. The guidelines discuss the goals and objectives of the units, the types of residents served, unit size and location, staffing, space and environmental factors, program evaluation, and quality assurance.

Multi-facility Nursing Home Corporations— Special Care Unit Guidelines

Some multi-facility nursing home corporations have guidelines for special care units in the nursing homes they own, Hillhaven Corp., which had 56 nursing homes with special care units in late 1990, has an extensive policy and procedures manual for the units (187). The manual was first developed in 1982 and was updated in 1984 and 1988 (337). It delineates the philosophy and treatment modalities of the units, their admission and discharge criteria and procedures, family services, use of restraints, staff training, and other features. The manual includes resident assessment instruments, guidelines for running a family support group, and a quality assurance checklist.

Unicare Health Facilities, which had 15 nursing homes with special care units in late 1990, also has a manual for its units, called "Lamplighter Units"

(281). The manual describes the care needs of nursing home residents with Alzheimer's disease and the philosophy, admission criteria, assessment procedures, staffing, and care methods of the company's special care units. The manual includes a resident assessment instrument. Other multi-facility nursing home corporations that have facilities with special care units may also have guidelines for the units.

The Joint Commission on Accreditation of Healthcare Organizations— Draft Surveyor Guidelines

Since 1989, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has been working on guidelines to assist its surveyors in evaluating special care units in the facilities it accredits. As noted earlier, JCAHO is a private organization that currently accredits about 1000 nursing homes in the United States (214). JCAHO's effort to develop guidelines evolved from concerns and questions raised by its surveyors about how to evaluate the increasing number of special care units they were seeing in nursing homes accredited by the commission (434).

JCAHO's surveyor guidelines, currently out for review in a fourth draft, are based on the commission's standards for all nursing homes (213,435). No changes have been made to the basic standards. Instead, statements have been added next to many of the standards to explain the implications of the standard for the care of residents with dementia and to describe the process surveyors should follow in evaluating and scoring the special care unit on that standard.

The 152-page fourth draft of the surveyor guidelines is much longer than the other guideline documents discussed in this section. It provides what is, in effect, a detailed answer to the question, "What constitutes appropriate care for nursing home residents with dementia?" Some commentators will undoubtedly disagree with some of its components, and certain of the components probably apply as much to nondemented as demented nursing home residents. There are also instances in which the guidelines tell surveyors to determine whether *appropriate* or *proper care* has been given, leaving open the question of what appropriate or proper care is; the frequency of these instances has decreased, however, in each successive draft of the

document. The guidelines are informative and thought-provoking at the least, and the commission is to be credited with creating comprehensive surveyor guidelines that fit within the broader context of its standards for all nursing homes.

JCAHO intends to pilot test the surveyor guidelines in the summer 1992 in six special care units in the Chicago area (435). Using the guidelines, two JCAHO surveyors will inspect the six units. Within 2 days, two representatives of the Alzheimer's Association will visit the same units. The surveyors' findings and the observations of the Alzheimer's Association representatives will be compared to determine whether the guidelines identify the problems that concern consumers.

Summary and Implications

The completed guideline documents discussed in the preceding sections are intended to educate and inform. They identify areas that require special consideration in the care of nursing home residents with dementia, but unlike the State regulations discussed earlier in the chapter, the guideline documents generally do not prescribe particular features for special care units. The JCAHO draft surveyor guidelines differ from the other guideline documents in that they do prescribe many detailed features for special care units, but the JCAHO guidelines are also intended primarily to educate and inform surveyors and to identify areas of special consideration in the care of residents with dementia.

The areas of special concern identified in the guideline documents are: activity programs, admission and discharge criteria, conditions of participation, cost and reimbursement, enforcement, family involvement, philosophy and goals, physical environment, physical restraints and psychotropic medications, plan of care, policies and procedures, quality assurance, research, resident assessment, resident rights, safety egress control, specialized services (e.g., physician, nursing, social work, and dietary services), and staffing. These areas of concern are not necessarily mutually exclusive, and some are addressed in only one of the guideline documents. Nevertheless, there appears to be some agreement at present about the areas of concern. The State regulations discussed earlier fit conceptually within the same areas of concern.

Having agreement about areas of concern is helpful in organizing a discussion about particular

features that might be desirable or required in special care units. On the other hand, agreement about areas of concern is not the same as agreement about particular features. For example, agreement that activity programs and physical environment are areas of concern does not constitute agreement about what the activity programs or physical design features should be. It is OTA's observation that in discussions about guidelines and regulations for special care units, agreement about areas of concern often masks considerable disagreement about particular features of the units and gives a misleading impression that there is consensus about at least some particular features that are desirable and should be required in special care units. Each of the completed guideline documents stresses the current uncertainty about the importance of particular features and the need for research to clarify many unresolved questions in this area.

Finally, it should be noted that like the State regulations for special care units discussed earlier, the completed guideline documents have not been developed in the context of the nursing home reform provisions of OBRA-87. Moreover, some of the specific guidelines in these documents duplicate provisions of OBRA-87 that apply to all nursing homes.

CONCLUSION

As of early 1992, six States had regulations for special care units. Five States were in the process of developing regulations, and other States were considering doing so. These State regulations are intended primarily to assure that special care units are not established and operated solely for marketing purposes and do actually provide something special for their residents. The regulations have been and are being developed in the absence of consensus among experts about the particular features that are necessary in a special care unit and research-based evidence to support requirements for any particular features.

Several public and private organizations have developed or are developing guidelines for special care units. These guidelines identify areas that require special consideration in the care of nursing home residents with dementia but generally do not prescribe particular features for special care units. The six completed guideline documents stress the current uncertainty about the importance of particu-

lar features and the need for research on the effectiveness of various approaches to the care of nursing home residents with dementia. These six guideline documents are not intended to be used for regulatory purposes.

The nursing home reform provisions of OBRA-87 create a broad, comprehensive regulatory structure aimed at assuring high-quality, individualized nursing home care for all residents. As described in this chapter, the provisions of OBRA-87 address many of the complaints and concerns of families and others about the care provided for residents with dementia in many nursing homes. The provisions of OBRA-87 rarely mention cognitive impairment or dementia, but the resident assessment system developed to implement OBRA-87 focuses clearly on the assessment of a resident's cognitive status and the problems and care needs that are common among nursing home residents with dementia. Once a

resident's needs are identified, OBRA regulations require that the needs be met.

If fully implemented, the provisions of OBRA-87 would improve the care of nursing home residents with dementia. The problem with OBRA-87 for nursing home residents with dementia is the same problem faced by State officials and others who are trying to develop regulations for special care units: i.e., the lack of agreement among experts about exactly what constitutes appropriate nursing home care for individuals with dementia and the lack of research-based evidence of the effectiveness of various approaches to their care. Solving this problem through Federal support for projects to evaluate different approaches to care may eventually provide a substantive basis for regulations. In the meantime, special care units are ideal settings for the necessary research.