

GAO

Report to the Honorable
Ron Wyden, U.S. Senate

May 1997

LONG-TERM CARE

Consumer Protection and Quality-of-Care Issues in Assisted Living





United States
General Accounting Office
Washington, D.C. 20548

**Health, Education, and
Human Services Division**

B-276379

May 15, 1997

The Honorable Ron Wyden
United States Senate

Dear Senator Wyden:

Many view assisted living as a promising option for providing care and help to an increasing number of frail elderly persons in a less costly and more homelike setting than nursing homes. Assisted living facilities (ALF) are similar to other residential care settings, such as board and care facilities, that offer housing, meals, protective oversight, and personal assistance to persons with physical or cognitive disabilities. Unlike nursing homes or many board and care settings, however, assisted living attempts to provide consumers with greater autonomy and control over their living and service arrangements.

Consumer demand for assisted living appears to be high, and Fortune magazine has identified it as one of the top three potential growth industries for 1997.¹ However, recent media accounts and other reports have highlighted instances where assisted living residents have been harmed or died as a result of alleged inadequate care and supervision. Because of your concern about these reports, you asked us to (1) provide a brief overview of the responsibilities of federal and state governments and ALFs in ensuring quality and protecting consumers living in ALFs and (2) identify issues that may require further research.

To conduct our work, we interviewed key officials and experts including federal and state officials, researchers, provider representatives, attorneys, and consumer advocates. In addition, we reviewed literature and current research on the subject. We performed our work from December 1996 through March 1997 in accordance with generally accepted government auditing standards.

¹Precise numbers of facilities and residents are difficult to obtain because there is no generally accepted definition of assisted living and no systematic means of counting these facilities. The Assisted Living Federation of America (ALFA) estimates that as many as 40,000 ALFs care for up to 1 million residents. Preliminary estimates by the Research Triangle Institute place the number of ALFs at between 17,000 and 25,000 depending on definitional criteria. Further study by the Research Triangle Institute, under contract to the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services (HHS), includes work to refine these estimates.

Results in Brief

A number of federal agencies have some jurisdiction over consumer protection and quality of care in ALFS. However, states have the primary responsibility for developing standards and monitoring care provided in ALFS. A recent compilation of state assisted living activities shows that state approaches to oversight vary. Some states regulate these facilities under standards previously developed for the board and care industry; some have developed standards and licensing requirements specifically for ALFS; others are in the process of developing them. But little is known about the effectiveness of the various state approaches to regulation and oversight or about the extent of problems assisted living residents may be experiencing. Moreover, some stakeholders are concerned that the rapid rate of assisted living market development may be outpacing many states' ability to monitor and regulate care furnished by providers.

Not only do state approaches to regulation of ALFS vary, the level and intensity of services provided in ALFS may also vary. According to some experts, consumers can find themselves in a facility unable to meet their expected needs. To determine whether the ALF setting is appropriate for them, prospective residents rely on facility-supplied information including contracts that set forth residents' rights and provider responsibilities. But one recent limited study found that contracts varied in detail and, in some cases, were vague and confusing. For example, a number of contracts stated only that services would be provided as the facility deemed appropriate, and few specified what occurs if a resident's health status declines. Overall, little is known about the accuracy and adequacy of information furnished to individuals and their families who are considering assisted living.

Many of these concerns about consumer protection and quality of care in assisted living have been identified by state governments, providers, and consumer advocates. Although several research efforts are under way currently, further research may be needed to determine (1) the nature and extent of problems related to consumer protection and quality of care that may be occurring, (2) the effectiveness and adequacy of existing models of oversight and regulation, and (3) the accuracy and adequacy of information provided to consumers and whether that information enables them to make informed choices about their care.

Background

Assisted living may be defined as a special combination of housing, personalized supportive services, and health care. It is designed to respond to the needs of individuals who require help with activities of

daily living (ADL),² but who may not need the level of skilled nursing care provided in a nursing home.³ However, there is no uniform assisted living model, and considerable variation exists in what is labeled an ALF. (See app. I for selected assisted living definitions.) For example, an ALF can be a small residential care home providing limited personal care assistance to a few residents; it may also be a large congregate living facility providing a variety of specialized health and related services to more than 100 residents.

Assisted living is usually viewed as a specific residential care setting along the continuum between independent living and a nursing home. ALFs are similar to board and care homes in that both may provide protective oversight and assistance with some ADLs and other needs such as medication administration.⁴ According to assisted living advocates, however, what may not be evident in board and care is the assisted living philosophy that emphasizes residents' autonomy, maximum independence, and respect for individual resident preferences. Moreover, ALFs may sometimes admit or retain residents who meet the level-of-care criteria for admission to a nursing home.

According to a 1993 study, many ALFs tend to serve a frail and vulnerable population who, in some cases, are more disabled than facility managers anticipated.⁵ This study also found some ALFs that cared for residents who used catheters or oxygen, and a few who used ventilators. A 1996 industry survey described the typical resident as⁶

- a single or widowed female,
- average age of about 84, and
- needing assistance with three ADLs such as continence and mobility.

²ADLs generally include eating, bathing, dressing, getting to and using the bathroom, getting in or out of a bed or chair, and mobility.

³Consumer demand for assisted living services appears to be high due to (1) an aging population, (2) increased geographic dispersion of families, and (3) fewer family caregivers available for a growing number of elderly persons.

⁴"Board and care" describes a wide variety of nonmedical, community-based, residential facilities—group homes, foster homes, adult homes, domiciliary homes, personal care homes, and rest homes.

⁵Rosalie A. Kane and Keren Brown Wilson, *Assisted Living in the United States: A New Paradigm for Residential Care for Frail Older Persons?* (Washington, D.C.: American Association of Retired Persons (AARP)/Public Policy Institute, 1993).

⁶These results are from a 1996 survey by ALFA and Coopers and Lybrand of 268 ALFs representing about 15,000 units in 35 states.

In addition, this survey found that 48 percent of residents had some cognitive impairment, such as Alzheimer's disease or other memory disorder, and 38 percent used walkers or wheelchairs.

Most residents pay for assisted living out of pocket or through other private funding.⁷ However, public sources of funding are available to pay for some residents in ALFs. For example, some states are looking to control their rising Medicaid costs through a variety of means that include using assisted living as an alternative to more expensive nursing home care. According to a 1996 report issued by the National Academy for State Health Policy, 22 states currently make Medicaid funds available for assisted living.⁸

States Primarily Responsible for Oversight of Assisted Living

A number of federal agencies bear some responsibility for aspects of consumer protection and quality of care in ALFs. (See app. II for a listing of federal agencies administering laws related to assisted living.) However, even where the federal government does play a role, most oversight functions rest with the states. For example, the Social Security Administration (SSA) and the Health Care Financing Administration (HCFA) have some authority related to assisted living. The Keys Amendment to the Social Security Act, which added section 1616(e), requires states to certify that they will establish, maintain, and enforce standards for any category of group living arrangement in which a significant number of Supplemental Security Income (SSI) recipients reside, or are likely to reside. Such settings may include board and care facilities or ALFs. HCFA requires states that have been granted a Medicaid home and community-based care waiver that includes ALF services to provide assurances that necessary safeguards have been taken to protect residents' health and safety. In both of these examples, the federal government grants broad discretion to states in carrying out their oversight responsibilities.

Few federal standards or guidelines govern assisted living, and states have the primary responsibility for oversight of care furnished to assisted living

⁷Assisted living developers have targeted elderly persons with moderate and upper incomes. The ALFA and Coopers and Lybrand survey found the average cost of assisted living in 1996 to be approximately \$2,150 per month.

⁸According to the American Public Welfare Association, 12 of these states have Medicaid home and community-based care waivers that include assisted living as a specific waiver service. Other states provide assisted living services under the waiver using a variety of different terms including domiciliary care homes, supported living, and adult congregate living facilities.

residents. In general, states' regulations tend to focus on three main areas: requirements for the living unit; admission and retention criteria; and the types and levels of services that may be provided. However, states vary widely on what they require. For example, state regulations differ in their (1) licensing standards concerning admission and discharge criteria, staffing ratios, and training requirements; (2) inspection procedures that specify frequency, notification requirements, and inspector training; and (3) the range of enforcement mechanisms that are available and used.

States also vary widely on the category or model under which they regulate these facilities. Some states regulate ALFS under existing board and care standards, some have created regulations specific to ALFS only, and others are studying how best to regulate these settings.⁹ Regarding states' regulation of board and care, our past reports and those by others have found enforcement of standards to be weak and authorized sanctions to be used infrequently.¹⁰ According to an AARP report, fines, even when authorized, were seldom imposed, and authority to ban admissions was limited and rarely used. But little is known about the effectiveness of board and care regulations as applied to ALFS. These reports also found the board and care home industry to have numerous quality problems, such as residents suffering from dehydration or denied adequate medical care. However, little is known about the specific quality-of-care problems ALF residents may be experiencing and whether their experiences differ from board and care residents.

Some states, including Oregon, Florida, and Connecticut, have developed specific regulations and licensing requirements for ALFS, and others are moving forward to develop them. According to consumer advocates and others, state efforts to regulate assisted living are challenged by the need to develop an approach that is flexible enough to allow for innovation in response to consumer demands and preferences yet that also protects residents who may be vulnerable due to physical or cognitive impairment. For example, Oregon has specific living unit requirements but not specific staffing requirements; for staffing, it requires that the facility's staffing is sufficient to deliver services specified in resident plans of care. Little is known about the effectiveness of these new approaches for ensuring quality of care in ALFS. (App. III includes a listing of recent state

⁹Robert L. Mollica and Kimberly Irvin Snow, State Assisted Living Policy: 1996 (Portland, Me.: National Academy for State Health Policy, Nov. 1996).

¹⁰For example, see Board and Care: Insufficient Assurances That Residents' Needs Are Identified and Met (GAO/HRD-89-50, Feb. 10, 1989) and Catherine Hawes and others, The Regulation of Board and Care Homes: Results of a Survey in the 50 States and the District of Columbia, Research Triangle Institute for AARP, Research Triangle Park, N.C.: 1993).

developments in assisted living policy and regulation as compiled by the National Academy for State Health Policy.)

Facilities' Responsibilities Outlined in Resident Contracts

Given the variation in what is labeled assisted living and the variety of ways states regulate these settings, consumers often must rely on information supplied to them by the provider to determine whether an assisted living setting is appropriate for their needs. Although marketing materials may contain information about facility standards and services, the written contract between the facility and the resident is the key document governing care to be provided. This document generally specifies the facility's responsibility to the resident, how the facility will respond to the resident's needs and changes in health status, how quality care will be maintained, and the resident's rights and responsibilities. However, little is known about the accuracy and adequacy of information furnished to individuals and their families. As a result, consumers may be at risk if they lack the necessary information to make informed decisions about their care.

A recent limited survey of industry practices noted that contracts had no standard format, varied in detail and usefulness, and in some cases were vague and confusing.¹¹ For example, none of the contracts examined mentioned how often services would be provided; a number of contracts stated only that services would be provided as the facility deemed appropriate. Furthermore, few specified what would occur if a resident's health status declined, such as what needed additional services would be provided, whether there are additional charges for those services, or whether the resident would be asked to leave because needed services could not be furnished.

According to some experts, a provision contained in some contracts that may raise consumer protection concerns is commonly referred to as the "negotiated risk agreement." When signing this agreement, the resident agrees to limit the facility's potential liability for specific risks the resident assumes. For example, a mobility-impaired resident advised by the provider not to use stairs may sign an agreement accepting the risk of harm from potential falls should the resident continue this activity. Perceiving unequal bargaining power between facilities and residents, some experts have raised concerns that written agreements, such as

¹¹John Richard Buck, "Assisted Living: An Uncharted Course," *Bifocal*, Newsletter of the Commission on Legal Problems of the Elderly, American Bar Association, Vol. 16, No. 4 (winter 1996), pp. 1-7, and "Can Your Loved Ones Avoid a Nursing Home: The Promise and Pitfalls of Assisted Living," *Consumer Reports* (Oct. 1995), pp. 656-59.

assisted living service contracts and negotiated risk agreements, may place the resident at risk of exploitation. However, we have no indication of whether, or how often, this occurs.

Issues Needing Further Research

Many of these consumer protection and quality-of-care concerns are shared by state governments, advocates, and provider organizations, and several groups are actively engaged in developing new oversight and regulatory models specific to assisted living. For example, two national initiatives under way currently are the Quality Initiative for Assisted Living and the Assisted Living Quality Coalition.¹² (A brief summary of these efforts and other current research is included in app. IV.) However, little is known about the extent of quality-of-care problems in ALFS, and few efforts have been made to assess the effectiveness of the various state quality assurance approaches. Furthermore, little is known about the accuracy and adequacy of information ALFS furnish to consumers and their families.

Further research is needed to determine (1) the nature and extent of problems related to consumer protection and quality of care that may be occurring in this developing market, (2) the effectiveness and adequacy of existing models of oversight and regulation and whether problems are being identified and corrected, and (3) the accuracy and adequacy of information provided to consumers and whether the information enables them to make informed choices about their care. Research into these questions should shed light on whether additional or new oversight requirements are needed to protect consumers and ensure quality of care in ALFS.

Agency Comments

Because no federal agency or program was the focus of our review, we did not obtain official agency comments. However, officials from the Office of the Assistant Secretary for Planning and Evaluation in HHS reviewed a draft of this report. They generally agreed with its contents and provided technical comments, which we incorporated as appropriate.

As agreed with your office, unless you publicly announce its contents earlier, we plan no further distribution of this report until 30 days from its date of issue. At that time, we will send copies to the Secretary of Health and Human Services, the Commissioner of Social Security, the

¹²The Quality Initiative for Assisted Living is an effort of the American Health Care Association (AHCA). The Assisted Living Quality Coalition is a joint project of AARP, ALFA, the Alzheimer's Association, and the American Association of Homes and Services for the Aging (AAHSA).

Administrator of the Health Care Financing Administration, relevant congressional committees, and other interested parties. Copies will also be made available to others on request.

If you or your staff have any questions about this report, please call me at (202) 512-7119 or Sandra K. Isaacson, Assistant Director, at (202) 512-7174. Other major contributors to this report were Eric R. Anderson and Connie J. Peebles.

Sincerely yours,

A handwritten signature in black ink, reading "Bernice Steinhardt". The signature is fluid and cursive, with the first name "Bernice" and last name "Steinhardt" clearly legible.

Bernice Steinhardt
Director, Health Services Quality
and Public Health Issues

Contents

Letter		1
Appendix I		12
Selected Assisted Living Definitions	U.S. Health Care Financing Administration	12
	American Association of Homes and Services for the Aging	12
	American Health Care Association	12
	Assisted Living Federation of America	13
Appendix II		14
Federal Agencies Administering Laws Related to Assisted Living	HCFA	14
	SSA	15
	AOA	15
	FDA	16
	HUD	16
	Department of Justice	16
	FTC	17
Appendix III		18
Recent State Developments in Assisted Living Policy and Regulation		
Appendix IV		25
Selected Current Research and Other Efforts	Completed Studies and Reports	25
	Ongoing Research and Other Efforts	30
Selected Bibliography		35

Abbreviations

AAHSA	American Association of Homes and Services for the Aging
AARP	American Association of Retired Persons
ACF	alternative care facility
ADL	activities of daily living
AHCA	American Health Care Association
ALF	assisted living facility
ALFA	Assisted Living Federation of America
AOA	Administration on Aging
ASPE	Assistant Secretary for Planning and Evaluation
FDA	Food and Drug Administration
FHA	Federal Housing Administration
FTC	Federal Trade Commission
HCBS	Home and Community-Based Services
HCFA	Health Care Financing Administration
HHS	Department of Health and Human Services
HUD	Department of Housing and Urban Development
IOM	Institute of Medicine
SSA	Social Security Administration
SSI	Supplemental Security Income

Selected Assisted Living Definitions

U.S. Health Care Financing Administration

HCFA has suggested the following assisted living definition for states to use with Medicaid home and community-based waivers (section 1915(c) of the Social Security Act), although the states may make changes to this definition in their waiver submission:

“Assisted living may be defined as services such as homemaker, chore, attendant care, companion services, medication oversight (to the extent permitted under State law), and therapeutic social and recreational programming, provided in a licensed community care facility, in conjunction with residing in the facility. This includes 24-hour on-site response staff to meet scheduled or unpredictable needs and to provide supervision of safety and security. Other individuals or agencies may also furnish care directly, or under arrangement with the community care facility, but the care provided by these other entities supplements that provided by the community care facility and does not supplant it.

“Care is furnished to individuals who reside in their own living units (which may include dually occupied units when both occupants consent to the arrangement) which may or may not include kitchenette and/or living rooms as well as bedrooms. Living units may be locked at the discretion of the client except when a physician or mental health professional has certified in writing the client is sufficiently cognitively impaired as to be a danger to self or others if given the opportunity to lock the door. (This requirement does not apply where it conflicts with the fire code.) Each living unit is separate and distinct from each other. The facility must have a central dining room, living room or parlor, and common activity center(s) (which may also serve as living or dining rooms). Routines of care provision and service delivery must be client-driven to the maximum extent possible. Assisted living services may also include home health care, physical therapy, occupational therapy, speech therapy, medication administration, intermittent skilled nursing services, and transportation specified in the plan of care.”

American Association of Homes and Services for the Aging

“Assisted living is a program that provides and/or arranges for the provision of daily meals, personal and other supportive services, health care, and 24-hour oversight to persons residing in a group residential facility who need assistance with activities of daily living and instrumental activities of daily living. It is characterized by a philosophy of service provision that is consumer driven, flexible, individualized, and maximizes consumer independence, choice, privacy, and dignity.”

American Health Care Association

“An assisted living setting is (1) a residential setting that provides or coordinates personal care services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services; (2) designed to minimize the need to move; (3) designed to accommodate the customer’s changing needs and preferences; (4) designed to maximize

individuals' dignity, autonomy, privacy, and independence; and (5) designed to encourage family and community involvement."

**Assisted Living
Federation of America**

"Assisted living is a special combination of housing, personalized supportive services and health care designed to respond to the individual needs of those who need help with activities of daily living but do not need the skilled medical care provided in a nursing home. Assisted living care promotes maximum independence and dignity for each resident and encourages the involvement of a resident's family, neighbors, and friends."

Federal Agencies Administering Laws Related to Assisted Living

For the most part, the states implement licensure and regulatory programs for assisted living in accordance with local needs and regulations. However, a number of federal laws affect consumer protection and quality of care issues in assisted living. Agencies administering these laws include the Health Care Financing Administration (HCFA), Social Security Administration (SSA), Administration on Aging (AOA), Food and Drug Administration (FDA), Department of Housing and Urban Development (HUD), Department of Justice, and Federal Trade Commission (FTC).

HCFA

Medicaid reimbursement for the direct care services component of assisted living, such as personal care, nursing services, and medication administration, may be available under Medicaid state plans or section 1915(c) waivers. But these payments do not cover room and board.¹³ Some states have been pursuing assisted living as a substitute for nursing home care, particularly in their Medicaid waiver programs. Currently, 12 states specifically provide assisted living for the elderly under a Medicaid waiver. Several others provide assisted living services under the waiver using different terms such as adult congregate living facilities, adult residential care homes, domiciliary care homes, supported living, and others.

Under a Medicaid waiver, HCFA requires state assurances that providers meet state standards for licensure or certification. In their application, states must cite applicable state codes and regulations for each service provided. If states require providers to meet standards other than, or in addition to, licensure or certification requirements, a copy of those standards and requirements must be included with the waiver application. Furthermore, states have to provide assurances to HCFA, as part of their waiver applications, that necessary safeguards have been put in place to protect residents' health and welfare. HCFA regional office staff conduct periodic, on-site waiver program reviews to ensure that states are implementing their waiver programs in accordance with Medicaid statutory and regulatory requirements as agreed to in their approved waiver requests. HCFA's policy is to conduct these reviews at least once in the first 3 years of the state's waiver and once every 5 years thereafter.

Medicare, on the other hand, does not reimburse for assisted living. If Medicare-reimbursed home health care or other services are provided to residents of assisted living facilities (ALF), HCFA has jurisdiction for

¹³In assisted living or board and care settings, the room and board portion may be paid by a combination of individual resident payments, Supplemental Security Income (SSI), and optional state payments.

oversight of these services only and not other services that may be furnished in the assisted living setting.

SSA

SSI payments, combined with an individual's income and optional state supplements to SSI, are a means of funding board and care and other community residential care facilities for low-income elderly and disabled persons. Some states combine SSI, which covers the cost of room and board, with Medicaid payments for the health and personal care component to create a means for low-income persons to be able to afford assisted living.

The Congress established a federal role in the regulation of board and care facilities in 1976 with the passage of the Keys Amendment to the Social Security Act.¹⁴ The Keys Amendment requires states to establish, maintain, and ensure enforcement of standards for any category of institutions, foster homes, or group living arrangements in which a significant number of SSI recipients reside or are likely to reside. These standards must cover such matters as admission policies, safety, sanitation, and protection of civil rights. States are required to report deficient facilities to SSA. If the facilities are found deficient, the agency can reduce the SSI benefits of any recipient living in such homes.¹⁵

AOA

AOA's role with respect to assisted living is exerted primarily through funding the state-run, long-term care ombudsman program. State ombudsmen (1) investigate and resolve nursing home residents' complaints, (2) train and supervise ombudsman volunteers, and (3) collect information to advise policymakers of needed changes in laws and regulations. The ombudsman program initially covered only residents of nursing homes. Eventually, it was expanded to include residents of board and care homes and similar facilities such as assisted living. States have discretion in determining priorities for their ombudsmen's efforts, and state activity with respect to board and care and assisted living varies. To obtain a better understanding of states' efforts in this area, AOA is now completing a compilation of fiscal year 1995 data from state ombudsman programs detailing their efforts with respect to board and care facilities.

¹⁴Effective March 31, 1995, responsibility for the Keys Amendment was transferred from the Department of Health and Human Services (HHS) to the independent SSA as required by statute.

¹⁵HHS was reluctant to do so because officials believed that the sanctions penalized the SSI recipients and not the facility. See *Board and Care: Insufficient Assurances That Residents' Needs Are Identified and Met* (GAO/HRD-89-50, Feb. 10, 1989).

FDA

FDA's primary jurisdiction over assisted living concerns drug safety. The Prescription Drug Marketing Act of 1987 governs the wholesale distribution of drugs. To the extent that an ALF receives and distributes drugs, it may be engaged in the wholesale distribution of them, and the provider would fall under applicable FDA rules. According to a recent study conducted for the American Association of Retired Persons (AARP), state and local pharmacy boards also interpret FDA guidelines so as to limit the role of assisted living providers in receiving and storing drugs for residents.¹⁶ As a result, many state licensure regulations may limit the assistance providers can give with residents' medications.

HUD

HUD provides funding to expand the supply of housing with supportive services for elderly persons. Capital advances are available to finance construction and rehabilitation of housing for low-income elderly persons. The recipient of the funding is responsible for arranging the provision and funding of supportive services appropriate to the assessed needs of the residents. Rental assistance may be provided to eligible, low-income elderly residents. In addition, the Federal Housing Administration, a part of HUD, provides mortgage insurance to facilitate the development and refinancing of nursing homes, intermediate care facilities, board and care homes, and ALFS. HUD indicates that to be eligible for the program, board and care homes and ALFS must (1) have five or more bedroom accommodations or units and (2) be licensed or certified by the appropriate state or local agency.

Department of Justice

The Department of Justice has responsibility for enforcing two laws that may affect assisted living. First, the Disability Rights Section of Justice protects the rights of persons with disabilities under the Americans With Disabilities Act. Among other things, the act prohibits discrimination on the basis of disability in places of public accommodation and establishes architectural accessibility requirements for new construction and alterations of commercial facilities. Second, under authority of the Civil Rights of Institutionalized Persons Act, the Special Litigation Section of Justice is responsible for protecting the constitutional and federal statutory rights of persons confined in certain institutions owned or operated by state or local governments, which may include ALFS. According to a Justice official, neither section currently has any cases involving residents in ALFS.

¹⁶Kane and Wilson, Assisted Living in the United States.

FTC

The Federal Trade Commission Act prohibits unfair or deceptive acts or practices in or affecting commerce. FTC applies this prohibition to misleading advertisements for health care services. FTC considers advertisements or promotions to be deceptive if (1) they contain a representation or omission of fact that is likely to mislead consumers acting reasonably under the circumstances and (2) the representation or omission is likely to affect a consumer's choice or use of a product or service. In addition, an advertiser must be able to substantiate any objective claim in an advertisement and must have this substantiation before the ad is run. For health-care-related services, FTC generally requires that claims be substantiated by scientific tests. The act's provisions would be relevant to ALFs to the extent that their marketing claims are consistent with the services they provide. According to an FTC official, its Service Industry Practices Section has not handled any cases specifically on assisted living.

Recent State Developments in Assisted Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living ^a	Status of state activity in assisted living
Alabama	Yes	Current state regulations license three assisted living categories based on the number of residents served. The Department of Health held two meetings on assisted living to obtain suggestions for revisions. The state Health Coordinating Council is reviewing assisted living.
Alaska	Yes	Statute passed in 1994. Regulations were effective in 1995. Services are reimbursed through a Medicaid Home and Community-Based Services (HCBS) waiver.
Arizona	No	Reimbursed as a Medicaid service through the Arizona Long Term Care Systems' managed care program (1115 waiver). In 1996, legislation expanded the pilot program statewide.
Arkansas	No	Licenses residential care facilities. No assisted living activity.
California	No	A work group was formed in 1996 to conduct a study of state approaches to assisted living, and the state's budget bill directed the Department of Health to submit a report and recommendations in January 1997. Currently licenses residential care facilities for the elderly.
Colorado	No	Licenses personal care boarding homes, and Medicaid reimbursement is available through an HCBS waiver.
Connecticut	Yes	Regulations were effective in December 1994. Licensure process implemented. Four facilities have been licensed.

(continued)

Appendix III
Recent State Developments in Assisted
Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living^a	Status of state activity in assisted living
Delaware	No	Task force is developing regulations that are expected to be issued in 1997. Legislation seeking Medicaid funding will be filed as part of the Division of Services for Aging and Adults With Physical Disabilities' budget.
Florida	Yes	Regulations issued in 1992. Legislative amendments were passed and new regulations issued in 1996. An HCBS waiver has been approved to serve 225 Medicaid recipients.
Georgia	No	Licenses personal care homes. Medicaid reimbursement is available through an HCBS waiver. No assisted living activity.
Hawaii	Yes	Legislation authorizing development of assisted living regulations was passed in 1995. Draft regulations were issued in November 1996 for comment.
Idaho	No	A concept paper was developed by the Residential Care Council in 1995. Legislation passed revising residential care facility rules. Further action on assisted living is being reviewed by the state agencies.
Illinois	No	The Illinois affiliate of the American Association of Homes and Services for the Aging created a task force to support assisted living. The task force developed assisted living legislation that is expected to be filed in the 1997 session. The legislature approved a series of demonstration projects related to assisted living but did not create a separate licensure category.
Indiana	No	The Aging Department is heading a task force that may file legislation for consideration in 1997.

(continued)

Appendix III
Recent State Developments in Assisted
Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living^a	Status of state activity in assisted living
Iowa	Yes	A law was passed that creates a certification process for assisted living. Draft rules will be prepared in 1996. Implementation is planned for 1997.
Kansas	Yes	Law was passed in 1995 defining assisted living. Regulations will be finalized in the fall of 1996.
Kentucky	Yes	Legislation was passed in 1996.
Louisiana	Yes	Draft regulations have been developed.
Maine	Yes	Legislation revising the state's assisted living program was passed in 1996, and regulations are being drafted. The legislation provides for several levels of assisted living and varying licensing based on the level of service provided. Services are reimbursed through Medicaid.
Maryland	Yes	Legislation was passed in 1996 based on a task force report.
Massachusetts	Yes	Legislation creating an assisted living certification process was signed in January 1995. Regulations have been issued. Certification process created for settings meeting specified criteria. Financing for services (Medicaid) and housing (SSI) is available for purpose built and conventional elderly housing projects. Sixty projects and 3,700 units have been certified.
Michigan	No	In 1995, the Department on Aging led a work group that reviewed current trends in assisted living but decided to maintain existing regulations. In 1996, a new group will be created to reevaluate the issue.
Minnesota	No	Assisted living has been implemented as a Medicaid service.
Mississippi	No	No activity.

(continued)

Appendix III
Recent State Developments in Assisted
Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living^a	Status of state activity in assisted living
Missouri	No	No activity to create assisted living has been identified. Medicaid reimbursement is available for residential care facilities.
Montana	No	Assisted living is covered in personal care facilities as a Medicaid waiver service.
Nebraska	No	The Department of Health has formed a task force to revise existing residential care facility rules and perhaps create a new licensure category with a higher level of care. Managed Long Term Care Work Group will also consider where assisted living fits in the continuum of care.
Nevada	No	Licenses residential care facilities for groups. No assisted living activity. Limited Medicaid reimbursement is available.
New Hampshire	No	No activity to create assisted living has been identified, although state officials view their existing regulations as equivalent to assisted living.
New Jersey	Yes	Regulations creating a new licensure category were implemented. Ten facilities have been licensed, 140 have been approved but not yet licensed, and 35 applications are pending. Regulations developing an assisted living model in elderly housing have been issued.
New Mexico	No	Assisted living has been added as a Medicaid waiver service.
New York	No	Contracts with 63 projects and 3,500 units have been approved. A request for proposal for 700 units in New York City was issued, and final selections have been made. A task force has been created to consider a separate licensure category for assisted living.

(continued)

Appendix III
Recent State Developments in Assisted
Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living^a	Status of state activity in assisted living
North Carolina	Yes	Legislation was passed in 1995 that defines assisted living residence as a category of adult care homes. Regulations revising the adult care home model and registration requirements for assisted living in elderly housing sites have been issued. Personal care is covered in adult care homes through Medicaid.
North Dakota	No	Assisted living services are funded through the state's Medicaid waivers and two state-funded service programs.
Ohio	No	Legislation was passed in 1993. Regulations implementing the bill were postponed pending review by a special committee in 1994. Legislation passed in 1995 repealed the statute and authorized funding for 1,300 assisted living Medicaid waiver slots effective July 1996. New rules governing residential care facilities were effective in September 1996, and a decision on submitting the Medicaid waiver has been delayed pending a study of the entire Medicaid program.
Oklahoma	No	A task force has been created to develop assisted living recommendations. A draft bill has been circulated and is being revised by the task force.
Oregon	Yes	Program rules operational. Supply continues to expand, with 69 facilities and 3,200 units licensed. Thirty projects are under construction or in the planning stages.
Pennsylvania	No	Personal care homes are licensed. The licensing agency and interest groups are considering renaming the category as assisted living, while other groups support creating a separate category with a higher level of care.

(continued)

Appendix III
Recent State Developments in Assisted
Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living^a	Status of state activity in assisted living
Rhode Island	Yes	About 45 residential care facilities and ALFs are licensed. New buildings offer units with private bath.
South Carolina	No	A task force has been formed. A report is expected in the fall of 1996.
South Dakota	Yes	Assisted living category exists in statute. Limited services allowed.
Tennessee	Yes	Legislation creating an ALF category was passed in 1996. A task force has been appointed to draft regulations.
Texas	No	Assisted living has been added to the Medicaid HCBS waiver. A task force was formed to develop regulations creating a new licensure category. The report made changes in the existing category but did not develop assisted living recommendations.
Utah	Yes	Program rules on ALF licensure were approved in 1995. Rules governing the buildings were also approved by a state board. An amendment to the Medicaid HCBS waiver to cover assisted living is being considered.
Vermont	No	The 1997 budget allows transfer of the Medicaid equivalent of 46 beds for community care and assisted living. The Department of Aging and Disabilities has formed a work group to draft the assisted living component of the program. In addition, the Department has implemented an enhanced residential care facilities program that provides \$50/day for 70 residents who meet the nursing home level of care criteria.
Virginia	Yes	Regulations allowing assisted living services in adult care residences were effective in February 1996.

(continued)

Appendix III
Recent State Developments in Assisted
Living Policy and Regulation

State	Legislation and/or regulations creating a specific category for assisted living^a	Status of state activity in assisted living
Washington	No	Rules covering assisted living as a Medicaid waiver service were issued June 1996. The 1995 budget transferred funding for 1,600 nursing facility beds to assisted living and community options. Medicaid has contracted with 70 facilities and serves 750 waiver clients.
West Virginia	No	Licenses personal care homes. No assisted living activity.
Wisconsin	Yes	Legislation certifying assisted living facilities and providing funding for a Medicaid HCBS program was passed in 1995 as part of the governor's budget. Regulations have been finalized. A Medicaid waiver is anticipated.
Wyoming	Yes	Regulations upgrading board and care rules were issued. Board and care facilities can also be licensed as ALFs in order to provide limited skilled nursing services and medication administration.

^aMay include existing or draft regulations creating a licensure category or certification process for assisted living. In addition, some states that do not have a specific licensure category or certification process do, however, cover assisted living in their Medicaid program.

Source: Robert L. Mollica and Kimberly Irvin Snow, *State Assisted Living Policy: 1996* (Portland, Me.: National Academy for State Health Policy, Nov. 1996). We did not independently verify the accuracy of this information, nor did we update it to reflect the current time period.

Selected Current Research and Other Efforts

The following two sections are an overview of recently completed studies and reports on assisted living and a summary of ongoing research and other efforts in this area.

Completed Studies and Reports

1. State Assisted Living Policy: 1996, Robert L. Mollica and Kimberly Irvin Snow (Portland, Me.: National Academy for State Health Policy, Nov. 1996).

This study reports on a 1996 survey of states conducted as part of the ongoing National Study of Assisted Living for the Frail Elderly, sponsored by the HHS Assistant Secretary for Planning and Evaluation (ASPE). The report analyzes, tabulates, and summarizes statutes, regulations, task force reports, and interviews with state officials in each of the 50 states on assisted living. This report profiles the 50 states' statutes, regulations, draft legislation, draft regulations, and processes for designing state policy as well as the particulars of their models for assisted living. The purpose of the overall HHS/ASPE study is to identify the place of assisted living in long-term care and its potential for meeting the needs of a growing number of elderly persons with disabilities.

The report finds that regulations that ensure the safety and quality of care in assisted living are limited. Regulations in most states set the parameters for assisted living, but owners and operators define the practice. ALFs in states that emphasize the consumer try to foster independence, dignity, privacy, and autonomy. Thirty-one states have or are implementing a state policy on assisted living. Fifteen states have existing licensure regulations for assisted living, and 9 are developing them. Twenty-two states reimburse or purchase assisted living under Medicaid; 6 states provide Medicaid payments in board and care settings. Thirteen states are studying recommendations for the development of assisted living rules.

2. Assisted Living: Reconceptualizing Regulation to Meet Consumers' Needs and Preferences, Keren Brown Wilson (Washington, D.C.: AARP/Public Policy Institute, 1996).

This report provides a framework for an outcome-oriented regulatory process for assisted living that emphasizes quality while facilitating the goals of maximizing consumers' independence, dignity, privacy, and autonomy. The paper states that no such framework currently exists. The author includes an examination of the effect of regulatory processes on the development and delivery of assisted living. As presented, the

framework reflects the discussions of a panel of 43 participants convened on October 13-14, 1995. The paper offers specific examples of how the framework might be operationalized as a system but does not offer a model for state legal or regulatory systems.

The framework defines assisted living as a residential setting that provides or coordinates safe and flexible personal care services with 24-hour supervision and assistance in an environment that minimizes the tenants' need for movement within or from the setting. Additionally, the framework specifies that ALFs have an organizational mission, service programs, and a physical environment that encourage family and community involvement. The framework also proposes quality standards in two components: (1) minimum licensing standards based on quantifiable or process-oriented requirements and (2) outcome goals for 11 areas of tenant autonomy, service provision, and the residential character of the setting. These quality standards are to be implemented through a monitoring process and a performance improvement process.

3. Best at Home: Assuring Quality Long-Term Care in Home and Community-Based Settings, ed. Jill C. Feasley (Washington, D.C.: National Academy Press, 1996).

The purpose of this study was to examine how consumers and their families, payers, and providers try to ensure high-quality care in home and community-based settings. The report sets out the conceptual framework and provisional design for a much larger Institute of Medicine (IOM) study that was to be conducted under the auspices of the 1992 reauthorization of the Older Americans Act and the Secretary of HHS. The 1992 reauthorization of the Older Americans Act called for an IOM study of the quality of board and care facilities. This broader IOM effort was intended to result in standards for board and care. However, this larger effort was not conducted because funds were not made available.

For the planning study, the authors reviewed the relevant literature; offered presentations at an invitational workshop attended by 27 consumers, researchers, and state officials; and engaged in the deliberations of a planning committee for the two studies. The members included experts in long-term care policy, regulation and accreditation, advocacy, and quality assurance and improvement in home and residential care services.

As a study plan, the report identified six major questions related to home and community-based residential care settings: (1) What key features define the services and their consumers? (2) What are the type, frequency, and severity of quality problems? (3) What factors enhance or impede the provision of quality care? (4) How can the appropriateness, effectiveness, and adequacy of current and proposed quality assessment and improvement strategies for services be optimized? (5) What role should consumers and their informal caregivers play in defining and evaluating quality? (6) Are national minimum standards or model standards needed to ensure the quality of care? The authors further suggest an exploration of the appropriate roles of federal, state, and local governments as well as private accreditation organizations in monitoring compliance with any such standards.

4. Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes, Research Triangle Institute and Brown University (Research Triangle Park, N.C.: Research Triangle Institute, Dec. 1995).

Sponsored by HHS, this study was initiated to help document the characteristics of board and care homes and their residents and assess the quality of care delivered to residents. The database included data gathered in 386 licensed and 126 unlicensed board and care facilities with 512 operators, 1,138 staff, and 3,257 residents in a purposive sample of 10 states. The study authors made site visits to all the board and care homes and interviewed operators, staff, and residents. They developed (1) measures for both the quality of care and quality of life in the homes and (2) indicators to describe the residents and facilities that were used in the analysis of the effect of regulation and licensure on quality.

The study found that increasing disability among residents makes safety and quality assurance issues especially pressing. The large number of unlicensed homes and the presence of unlicensed ALFs raise questions about the regulatory role of the states with regard to places that provide essentially the same type of care and services as licensed board and care homes. The mix of physically frail elderly, cognitively impaired elderly, and residents with mental illness and developmental disabilities was challenging. The average resident was older and more disabled than a decade ago; most board and care homes were small, but the majority of residents were in homes with more than 50 beds. In the 10 study states, an estimated 12 percent of homes were unlicensed, and 27 percent of the beds were in unlicensed homes. Licensure alone was effective in ensuring that homes provided care above a threshold of minimum performance.

Regulatory systems reduced the prevalence of unlicensed homes; effectively promoted safety, quality of life, and quality of care; and did not produce an excessively institutional model of care. The authors suggest that the federal government can support state and provider efforts to improve the quality of care by developing and disseminating information about changes in the long-term-care sector.

5. Serving People With Dementia: Regulating Assisted Living and Residential Care Settings, Joan Hyde (Wellesley, Mass.: Hearthstone Press, 1995).

The purpose of this policy research project was to describe the needs of people with Alzheimer's and related disorders in assisted living settings in the United States and to recommend "Alzheimer's friendly" regulatory language to support those needs. To meet this objective, the author developed and applied a systematic checklist to a content analysis of a sample of existing and proposed assisted living and residential care laws and regulations in 10 states. The checklist was revised following interviews with a sample of providers, regulators, consumers, and researchers in the 10 states. Draft model regulatory language and principles were developed and distributed to 52 experts, whose responses were incorporated into the report.

This study found that there was little consistency in residential care regulations from one state to the next, making comparisons difficult. There were major differences in the degree to which regulations reflected an understanding of the large percentage of assisted living residents who suffer from cognitive impairment; most of these states' assisted living regulations did not address important issues related to serving Alzheimer's residents. The most serious regulatory obstacles to serving people with dementia were restrictive admission and discharge criteria, along with lack of recognition of the family role in decision-making. Lack of financial support for low-income elderly was another key problem among the states. The author found a heavy emphasis on a medical model of care, evident in staffing requirements and in assessment and service planning. States with commissions or advisory boards that dealt with dementia issues tended to be more "Alzheimer's friendly" in practice even if the regulations, as strictly read, did not support serving this population.

6. Assisted Living in the United States: A New Paradigm for Residential Care for Frail Older Persons? Rosalie A. Kane and Keren Brown Wilson (Washington, D.C.: AARP/Public Policy Institute, 1993).

The purpose of the study was to provide a snapshot review of recent developments in assisted living in the United States. The authors surveyed 63 assisted living programs in 21 states as well as all licensed assisted living programs in Oregon. In addition, they interviewed for perspective and experience a purposive sample of 16 developers plus 50 key informants selected to include trade, professional, and consumer representatives, researchers, and federal officials. Finally, the authors performed case studies of the development of assisted living in 14 states.

The study found that despite some central trends, variation in assisted living was substantial across the states. Settings varied in their features, as did the levels of disability served. The average length of stay for all programs was 26 months. Similarly variable were patterns of internal staffing and the use of consultants and home health contractors, although the trend was toward flexible use of labor and minimizing job differentiation. According to the study authors, state policy and regulation have shaped, and have often hindered, the evolution of assisted living and its characteristics, which are often market driven. Assisted living can effectively serve low-income people while holding promise as a cost-effective form of care. The study suggested ways in which state policies could enhance the growth and viability of moderate-cost and small facilities. The authors also recommended that quality outcomes, including resident satisfaction, be emphasized over prescriptive standards and that environmental enhancements, such as private units, be mandated under assisted living licensure. Otherwise, developers tend not to provide them for low-income consumers.

7. Policy Synthesis on Assisted Living for the Frail Elderly, Lewin-VHI, Inc. (Washington, D.C.: HHS, ASPE, Dec. 16, 1992).

The purpose of this study was to provide a broad overview of issues related to assisted living for the frail elderly. The authors reviewed and analyzed more than 350 published and unpublished books, reports, and documents and conducted extensive telephone interviews with policymakers, association representatives, academicians, and researchers. The study describes assisted living programs in 10 states (Florida, Maine, Maryland, New York, and Oregon among them) and reviews such concerns as regulation, funding, and evaluation results. Several chapters discuss further research questions to pursue. These were partially suggested by 40 policymakers, researchers, and practitioners who used the study as a discussion springboard in a November 20, 1992, meeting on assisted living

for the frail elderly sponsored jointly by ASPE and the National Academy for State Health Policy.

This study reported that existing research found that frail elderly people expressed greater satisfaction with assisted living settings than with nursing home care. Assisted living has the unique opportunity to structure a regulatory approach with hindsight from nursing home regulation. Many experts believe that a “hallmark” of assisted living regulation should be flexibility. With regard to the financing of ALFS, three trends were noted. First, resources have shifted over time from producing new housing units to supporting rental assistance in existing housing. Second, new programs emphasized a combination of “bricks and mortar” financing and services financing. Third, the Congress tended to encourage partnerships in housing development between the federal government and the states, partnerships in which the federal government contributes policy direction and the states develop solutions that fit their individual needs.

Ongoing Research and Other Efforts

1. National Study of Assisted Living for the Frail Elderly, sponsored by the HHS ASPE, the Administration on Aging, and the National Institute on Aging. A contract for a comprehensive 2-year study was awarded to Research Triangle Institute. The project team includes representatives of The Lewin Group, the University of Minnesota National Long-Term Care Resource Center, and the National Academy for State Health Policy.

The purpose of the study is to identify where assisted living fits into the spectrum of long-term-care facilities and its potential for meeting the needs of the growing number of elderly persons with disabilities. The study aims to identify trends, barriers, and factors in supply and demand; determine how well supply meets the central tenets of assisted living; and examine selected outcomes, including resident satisfaction, autonomy, affordability, and potential to provide nursing-home-level care. The overall study design includes interviews with lenders, developers, owners, consultants, and managers. The project team has conducted annual surveys of all state licensing and housing agencies involved in assisted living, as well as Medicaid agencies that fund assisted living. The design also includes a telephone survey of a national probability sample of 2,500 facilities. Furthermore, the design calls for interviews with operators, staff, and residents at on-site visits to 690 facilities. Finally, focus groups consisting of current and former residents and their family members will help the study authors define quality as consumers of ALFS see it.

2. Assisted Living Quality Initiative: Building a Structure That Promotes Quality, a working document of the Assisted Living Quality Coalition consisting of the Alzheimer's Association, the American Association of Homes and Services for the Aging, AARP, and the Assisted Living Facilities Association of America,¹⁷ August 1, 1996.

The purpose of the paper is to provide a possible blueprint for change in the way quality is promoted in long-term care and to present a multifaceted approach to assuring quality and promoting improvement in assisted living. The paper presents guidelines to states for establishing minimum standards for providers of assisted living. The coalition's quality initiative includes recommendations for state licensure review; daily quality monitoring for constant improvement in clinical, functional, and quality-of-life outcomes; and state enforcement and penalties when there is an identified threat to health, safety, or quality.

The paper describes an outcomes-oriented system that would require institutionalizing (1) the development of guidelines for state standards and for quality indicators by credible independent bodies; (2) the conducting of research on the validation of quality indicators, risk adjustments, and predictors of quality outcomes; (3) the analysis of data by a sophisticated research organization that can develop normative guidelines for interpreting the results and the reporting of those data and results; and (4) consulting services for improving performance, together with the involvement of a state agency and possible roles for an independent, private body to act as a state agent in monitoring data collection and quality improvement.

3. The Quality Initiative for Assisted Living, draft plan (Washington, D.C.: American Health Care Association, June 26, 1996).

The draft plan suggests a framework for a quality-measurement system that would focus on service outcomes and customer satisfaction, defines assisted living services, and outlines a national service philosophy based on independence and choice for residents of all incomes. The plan has three major components. First are expectations for facilities that are broad statements in the areas of services, environment, customer protection, and management responsibilities. Second are service outcome indicators. Examples provided in the document are those for nursing home settings. Service outcome indicators specifically for assisted living are currently

¹⁷The Assisted Living Facilities Association of America recently changed its name to the Assisted Living Federation of America.

being developed. Third are customer satisfaction indicators developed by the University of Wisconsin and the Gallup Organization. These were created to measure and evaluate the degree to which the assisted living residents are satisfied with the setting and the quality of services.

4. Resident Centered Care in Assisted Living, Donna L. Yee, Ph.D., and John A. Capitman, Ph.D. (Waltham, Mass.: Brandeis University).

This exploratory study describes residents' experiences in assisted living programs. The study of 20 assisted living programs and 400 residents focuses on three dimensions: (1) personal choice and lifestyle, (2) getting appropriate and timely care, and (3) community participation opportunities. Reports of study findings have been submitted for publication. The study raises several serious issues and concerns about assisted living. In general, findings indicate much variation among programs in service packages offered, resident characteristics, care needs of residents, staffing, and involvement of the sponsor. Levels of service reported by residents did not generally coincide with individual needs and preferences, particularly in helping residents get needed care and in offering opportunities for participation. In addition, the study finds that (1) resident needs assessments are often prepared by the marketing person and filed away without periodic reassessment of resident needs; (2) resident care is rarely coordinated by personnel in different parts of the facility; (3) adequacy of staffing levels are difficult to determine since the resident's perception of purchasing a relatively protected environment can easily conflict with the provider's definition of what state regulations "allow" them to do (that is, the extent of skilled or personal care they can provide) and the provider's commitment to shareholder expectations; (4) documentation rarely reflects how the array of services provided meets specific needs of individual residents; and (5) the touted new paradigm of provider and resident risk-sharing (that is, negotiating a resident's desire for an independent lifestyle with his or her need for care) may result in neglectful care more than in new ways to support independent living for persons needing long-term care.

5. Comparative Study of Alternative Alzheimer's Care Facilities in Minnesota, Leslie Grant, Ph.D. (Minneapolis, Minn.: University of Minnesota).

This study, funded by the Alzheimer's Association, looks at alternative care facilities (ACF)—including ALFs, board and care homes, group homes, and other residential care alternatives to nursing homes—to evaluate how

responsive ACFs are to the needs of persons with Alzheimer's and their family caregivers. The study (currently in its first year) involves a 3-year, phased research design. Phase one is a telephone survey to collect descriptive information about the characteristics of 300 to 400 ACFs in Minnesota. Phase two involves field research conducted in 120 ACFs serving persons with Alzheimer's disease or related dementia to develop a classification system (ACF typology) based on dementia-specific environmental, staffing, and program features. Phase three is a longitudinal analysis of outcomes in 96 persons with Alzheimer's disease and 96 of their family caregivers over a 6-month period in 24 ACFs stratified by the ACF typology. A comparative analysis of outcomes has been completed (1) across the ACF typology and (2) between ACF and nursing home residents with dementia (using data from an ongoing study of dementia care in Minnesota nursing homes).

6. Effectiveness of Assisted Living in Oregon, Rosalie Kane (Minneapolis, Minn.: University of Minnesota).

The study, funded by the Robert Wood Johnson Foundation, evaluates the Oregon Assisted Living Program to assess who is being served, with what effects, and at what costs. The research has three components: (1) a longitudinal study of 600 assisted living tenants and 600 nursing home residents, with participants being interviewed three times over the course of a year; (2) a case study to determine the perceptions of key informants regarding assisted living and ways it should be defined; also included are interviews with assisted living program administrators to assess such issues as staffing patterns, admission procedures, and discharge criteria; and (3) a macro study of trends in the supply, price, and occupancy rates/caseloads of long-term care (assisted living programs, nursing homes, residential care facilities, adult foster homes, and home care) in Oregon since the inception of assisted living. The study will be completed in spring 1998.

7. Annual Report of State Ombudsmen Activity, U.S. Administration on Aging (Washington, D.C.: forthcoming).

AOA is required to prepare and submit an annual report to the Congress on state long-term-care ombudsman program activity. The current report, expected to be issued by early April 1997, contains detailed caseload data and is broken out to include activity related to board and care settings in addition to nursing homes. This report will present detailed fiscal year 1995 ombudsman program activity from 29 states related to board and

care facilities. (Next year's report will cover program activity from all states.) Data will include (1) the number of board and care or similar facilities in the state covered by the ombudsman mandate, (2) the number of facility visits, (3) the number and type of complaints and their disposition by type of facility, and (4) the type of complainant by type of facility.

Selected Bibliography

Approaches to Quality Under Home and Community-Based Services Waivers. HCFA, Medicaid Bureau. Washington, D.C.: November 1993.

Assisted Living Quality Initiative: Building A Structure That Promotes Quality, a Working Document. Assisted Living Quality Coalition. August 1, 1996.

Blanchette, Katherine. New Directions for State Long-Term Care Systems Volume III: Supportive Housing. #9701. Washington, D.C.: AARP/Public Policy Institute, February 1997.

Buck, John Richard. "Assisted Living: An Uncharted Course." Bifocal, Newsletter of the Commission on Legal Problems of the Elderly, American Bar Association, Vol. 16, No. 4 (winter 1996), pp. 1-7.

"Can Your Loved Ones Avoid a Nursing Home: The Promise and Pitfalls of Assisted Living." Consumer Reports (Oct. 1995), pp. 656-59.

Clemmer, Elizabeth. "Assisted Living and Its Implications for Long-Term Care." Issue Brief, No. 20. Washington, D.C.: AARP/Public Policy Institute, February 1995.

Coleman, Nancy, and Joan Fairbanks. "Licensing New Board and Care for the Elderly." St. Louis University Public Law Review, Vol. X, No. 2 (1991), pp. 521-30.

Hawes, Catherine, and others. A Description of Board and Care Facilities, Operators, and Residents. Report prepared for HHS/ASPE under contract no. DHHS-500-89-0031. Research Triangle Park, N.C.: Research Triangle Institute and Brown University, December 1995.

_____. The Regulation of Board and Care Homes: Results of a Survey in the 50 States and the District of Columbia. Research Triangle Park, N.C.: Research Triangle Institute for AARP, 1993.

Hyde, Joan, Ph.D. Serving People With Dementia: Regulating Assisted Living and Residential Care Settings. Wellesley, Mass.: Hearststone Press, November 1995.

Best at Home: Assuring Quality Long-Term Care in Home and Community-Based Settings. IOM. Washington, D.C.: National Academy Press, 1996.

Kane, Rosalie A., and Keren Brown Wilson. Assisted Living in the United States: A New Paradigm for Residential Care for Frail Older Persons? Washington, D.C.: AARP/Public Policy Institute, 1993.

Manard, Barbara, Ph.D., and others. Policy Synthesis on Assisted Living for the Frail Elderly. Report prepared for HHS/ASPE under contract no. DHHS-100-89-0032. Lewin-VHI, December 16, 1992.

Mollica, Robert L., and Kimberly Irvin Snow. State Assisted Living Policy: 1996. Report prepared for HHS/ASPE under contract no. DHHS-100-94-0024, with additional support from the National Institute on Aging, Administration on Aging, and the Alzheimer's Association. Portland, Me.: National Academy for State Health Policy, November 1996.

National Study of Assisted Living for the Frail Elderly: Literature Review Update. Lewin-VHI, under subcontract to Research Triangle Institute. Report prepared for HHS/ASPE under contract no. DHHS-100-94-0024, with additional support from the National Institute on Aging, Administration on Aging, and the Alzheimer's Association. Research Triangle Park, N.C.: February 1996.

Phillips, Charles, and others. Report on the Effects of Regulation on the Quality of Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes. Report prepared for HHS/ASPE under contract no. DHHS-500-89-0031, Research Triangle Institute and Brown University, Research Triangle Park, N.C.: December 1995.

"Quality of Board and Care Homes Serving Low-Income Elderly: Structural and Public Policy Correlates." Journal of Applied Gerontology, Vol. 12, No. 2 (June 1993), pp. 225-45.

Siemon, Dorothy, Stephanie Edelstein, and Zita Dresner. "Consumer Advocacy in Assisted Living." Clearinghouse Review (Oct. 1996), pp. 579-88.

U.S. General Accounting Office. Board and Care Homes: Elderly at Risk From Mishandled Medications (GAO/HRD-92-45, Feb. 7, 1992).

_____. Board and Care: Insufficient Assurances That Residents' Needs Are Identified and Met (GAO/HRD-89-50, Feb. 10, 1989).

Selected Bibliography

Wilson, Keren Brown. Assisted Living: Reconceptualizing Regulation to Meet Consumers' Needs and Preferences. Washington, D.C.: AARP/Public Policy Institute, 1996.

Ordering Information

The first copy of each GAO report and testimony is free. Additional copies are \$2 each. Orders should be sent to the following address, accompanied by a check or money order made out to the Superintendent of Documents, when necessary. VISA and MasterCard credit cards are accepted, also. Orders for 100 or more copies to be mailed to a single address are discounted 25 percent.

Orders by mail:

**U.S. General Accounting Office
P.O. Box 6015
Gaithersburg, MD 20884-6015**

or visit:

**Room 1100
700 4th St. NW (corner of 4th and G Sts. NW)
U.S. General Accounting Office
Washington, DC**

**Orders may also be placed by calling (202) 512-6000
or by using fax number (301) 258-4066, or TDD (301) 413-0006.**

Each day, GAO issues a list of newly available reports and testimony. To receive facsimile copies of the daily list or any list from the past 30 days, please call (202) 512-6000 using a touchtone phone. A recorded menu will provide information on how to obtain these lists.

For information on how to access GAO reports on the INTERNET, send an e-mail message with "info" in the body to:

info@www.gao.gov

or visit GAO's World Wide Web Home Page at:

<http://www.gao.gov>

**United States
General Accounting Office
Washington, D.C. 20548-0001**

**Bulk Rate
Postage & Fees Paid
GAO
Permit No. G100**

**Official Business
Penalty for Private Use \$300**

Address Correction Requested

