

Testimony

Before the Special Committee on Aging, U.S. Senate

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ASSISTED LIVING

Quality-of-Care and  
Consumer Protection Issues

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Health Financing and Public Health Issues  
Health, Education, and Human Services Division



G A O

Accountability \* Integrity \* Reliability

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# Assisted Living: Quality-of-Care and Consumer Protection Issues

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Mr. Chairman and Members of the Committee:

We are pleased to be here today to discuss quality-of-care and consumer protection issues in assisted living. Assisted living facilities are becoming an increasingly popular option for providing long-term care for the elderly in what can be a less costly and more homelike setting than nursing homes. Current estimates of the number of assisted living beds in the United States range from 800,000 to 1.5 million, and consumer demand is expected to grow significantly as the projected number of elderly Americans in need of long-term care doubles over the next 20 years.

Assisted living facilities offer a combination of housing, meals, personal support services, and, in some cases, health care for their residents. Although most assisted living is paid for privately by individuals and their families, many states are using Medicaid to fund services and care for residents in assisted living facilities, and others are considering whether assisted living can be a cost-effective alternative to publicly funded nursing home care for some persons. At the same time as interest in assisted living has grown, concerns about quality of care and consumer protection in assisted living have been raised in recent media accounts and other reports.

The information I am presenting is based on a report we are issuing to your Committee today that examined assisted living in four states—California, Florida, Ohio, and Oregon.<sup>1</sup> My statement focuses on four main issues:

- residents' needs and the services provided in assisted living facilities;
- the extent to which facilities provide consumers with sufficient information for them to choose a facility that is appropriate for their needs;
- the four states' approaches to oversight of assisted living; and
- the types of quality-of-care and consumer protection problems they identify.

Our findings are based on an analysis of responses to a mail survey of facilities in these four states, an evaluation of the facilities' marketing materials and contracts, interviews with state officials, a review of relevant state statutes and regulations, visits to 20 assisted living facilities, interviews with more than 90 assisted living residents or family members,

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<sup>1</sup>Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States (GAO/HEHS-99-27, Apr. 26, 1999).

and an analysis of state data on verified quality-of-care and consumer protection problems in assisted living facilities.<sup>2</sup>

In brief, we found that assisted living facilities vary widely in the types of services they provide and the residents they serve. They range from small, freestanding, independently owned homes with a few residents to large, corporately owned communities that offer both assisted living and other levels of care to several hundred residents. Some assisted living facilities offer only meals, housekeeping, and limited personal assistance, while others provide or arrange for a range of specialized health and related services. They also vary in the extent to which they admit residents with certain needs and whether they retain residents as their needs change.

Given the variation in what is labeled assisted living, prospective residents must rely on information supplied to them by facilities to select one that best meets their needs and preferences. However, we found that, in many cases, assisted living facilities did not routinely give consumers sufficient information to determine whether a particular facility could meet their needs, for how long, and under what circumstances. For example, many facilities did not provide prospective residents with written information on such key issues as the amount of assistance they could expect to receive with medications, the circumstances under which the cost of services might change, or when they could be required to leave if their health changes. Moreover, we identified numerous examples of vague, misleading, or even contradictory information contained in written materials that facilities provide to consumers.

The states have the primary responsibility for the oversight of care furnished to assisted living facility residents. All four states we reviewed have licensing requirements that must be met by most facilities providing assisted living services, and state licensing agencies routinely inspect or survey facilities to ensure compliance with state regulations. However, the licensing standards as well as the frequency and content of the periodic inspections vary across the states. The licensing agencies also respond to complaints they receive related to potential violations of state regulations. In addition, the long-term care ombudsman agency in all four states and the Adult Protective Services (APS) agency in Florida and Oregon

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<sup>2</sup>We sent our mail survey to 955 randomly selected facilities of 2,652 identified potential providers of assisted living in the four states. We received responses from 721 facilities, or 75 percent of those we surveyed, 622 of which identified themselves as providers of assisted living services. Our analysis of quality-of-care and consumer protection issues was based on a review of state licensing agency deficiencies, ombudsman complaints, and adult protective service allegations that state officials verified in a sample of 753 facilities in these states.

investigate complaints or allegations of problems involving residents of assisted living facilities.

Given the absence of any uniform standards for assisted living facilities across the states and the variation in their oversight approaches, the results of state licensing and monitoring activities on quality-of-care and consumer protection issues also vary, including the frequency of identified problems. However, using available inspection surveys and reports from the other oversight agencies in the four states, we determined that the states cited more than 25 percent of the 753 facilities in our sample for five or more quality-of-care or consumer protection related deficiencies or violations during 1996 and 1997. Eleven percent of these facilities were cited for 10 or more problems during this time period. Most of the problems identified by the state agencies were related to quality-of-care rather than consumer protection issues. While data were not available to assess the seriousness of each identified problem, many problems seemed serious enough to warrant concern. Frequently identified problems included facilities providing inadequate or insufficient care to residents; their having insufficient, unqualified, and untrained staff; and their not providing residents appropriate medications or storing medications improperly. State officials attributed most of the common problems identified in assisted living facilities to insufficient staffing and inadequate training, exacerbated by high staff turnover and low pay for caregiver staff.

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## Background

Assisted living is usually viewed as a residential care setting for persons who can no longer live independently and who require some supervision or help with activities of daily living (ADL) but may not need the level of skilled care provided in a nursing home. It is promoted by assisted living advocates as a long-term care setting that emphasizes residents' autonomy, independence, and individual preferences and that can meet their scheduled and unscheduled needs for assistance. Typically, assisted living facilities provide housing, meals, supervision, and assistance with some ADLs and other needs such as medication administration. However, there is no uniform assisted living model, and considerable variation exists in the types of facilities or settings that hold themselves out to be an assisted living facility. In some cases, assisted living facilities may serve residents who meet the level-of-care criteria for admission to a nursing home.

Unlike residents of nursing homes, the majority of whom receive some support from Medicaid or Medicare, most residents of assisted living facilities pay for care out of pocket or through other private funding.<sup>3</sup> However, public sources of funding are available to help pay for services for some residents. For example, some states are attempting to control rising Medicaid costs by encouraging the use of assisted living as an alternative to more expensive nursing home care. Currently, 32 states use Medicaid funds to reimburse for services provided to Medicaid beneficiaries residing in assisted living facilities.<sup>4</sup> However, Medicaid payments do not cover the cost of room and board in assisted living facilities. A combination of individuals' personal resources, residents' Supplemental Security Income (SSI) payments, and optional state payments pay for these costs.

The states have the primary responsibility for overseeing the care that assisted living facilities provide residents, and few federal standards or guidelines govern assisted living.<sup>5</sup> The four states we reviewed vary widely in what they require of these facilities. Generally, state regulations 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. Some states have set very general criteria for the type of resident who can be served and the maximum level of care that can be provided, while other states have set more specific limits in these areas, such as not serving residents who require 24-hour skilled nursing care.

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## **Assisted Living Facility Services and Resident Needs Vary Widely**

A wide variety of services are available to residents in assisted living, and most facilities provide oversight to monitor and supervise their residents. These oversight responsibilities generally include providing 24-hour supervision; monitoring changes in residents' health and functioning; notifying a resident's physician, family, or other responsible person when the resident's condition changes; and providing regular health or wellness checks. Assisted living facilities in our survey reported that they usually

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<sup>3</sup>Medicaid is the federal-state health financing program for low-income and aged, blind, and disabled people. Medicare finances health care for most Americans over age 65 and the disabled. In 1999, the federal government is projected to pay \$39 billion for nursing home care, mostly through Medicaid.

<sup>4</sup>See *State Assisted Living Policy: 1998* (Portland, Me.: National Academy for State Health Policy, June 1998). States often use the authority available under section 1915(c) of the Social Security Act, which enables them to fund nursing services in a home and community-based setting rather than in an institutional setting.

<sup>5</sup>For further information on federal programs' responsibility related to assisted living, see *Long-Term Care: Consumer Protection and Quality-of-Care Issues in Assisted Living* (GAO/HEHS-97-93, May 15, 1997).

provide housekeeping, laundry, meals, transportation to medical appointments, special diets, and assistance with medications. Many facilities also provide skilled nursing services, skilled therapy services, and hospice care for their residents. More specialized services, such as intravenous (iv) therapy and tube feeding, are least likely to be available. Some services may be provided by facility staff or by staff under contract to the facility. In other cases, the facility may arrange with an outside provider to deliver some services, with residents paying the provider directly, or residents may arrange and pay for services on their own.

We found considerable variation among facilities and among states in the needs of the residents they serve. The facilities we visited have some residents who are completely independent and ambulatory, some who have severe cognitive impairments, and some who are bedridden and require significant amounts of skilled nursing care. Residents of assisted living facilities typically need the most assistance from facility staff with medications and bathing. Assistance with dressing and toileting or incontinence care are the next most frequently cited needs, and assistance is needed to a lesser extent with eating, transferring, and walking. The highest level of resident need for staff assistance with ADLs was reported among facilities in Oregon and those in Florida licensed as extended congregate care facilities. In addition, residents often have some degree of cognitive impairment, such as significant short-term memory problems, disorientation much of the time, or Alzheimer's disease or another form of dementia.

The ability of residents to remain in a facility as their health declines or their needs change, commonly referred to as aging in place, is determined largely by admission and discharge criteria. There is considerable variation across the states in these criteria, some of which comes from state regulations, some the facilities' choice of whom to serve, and some the particular services a facility chooses to provide or make available. For example, facilities in Oregon are more likely to admit and retain residents with a higher level of need than those in other states. Facilities responding to our survey vary in terms of resident needs they accept on admission and the circumstances under which they retain or discharge residents who develop certain needs or conditions after being admitted. Although some facilities may not admit residents with a particular need or condition, they do not necessarily discharge them if they develop that need. For example:

- More than 75 percent of the facilities reported that they admit residents who have mild to moderate memory or judgment problems, are

incontinent but can manage on their own or with some assistance, have a short-term need for nursing care, or need oxygen supplementation.

- Less than 10 percent of the facilities admit residents who are bedridden, require ongoing tube feeding, need a ventilator to assist with breathing, or require IV therapy, and most facilities discharge residents who develop these needs.
- Most facilities in Oregon indicated that they do not admit people who are bedridden, but half typically retain anyone who becomes bedridden while a resident.

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## **Consumers May Lack Adequate Information to Select a Facility That Best Meets Their Needs**

Given the variation in what is labeled assisted living, prospective residents must rely primarily on information supplied to them by facilities to select one that best meets their needs and preferences. They can obtain information in a variety of ways, including written materials, facility tours, personal interviews, and personal recommendations. However, in order to help prospective residents compare facilities and select the most appropriate setting for their needs, key information should be provided in writing and in advance of their decision to apply for admission. Yet we found that written material often does not contain key information; facilities do not routinely provide prospective residents with important documents, such as a copy of the contract, to use as an aid in decisionmaking; and written materials that are available are sometimes confusing or even misleading.

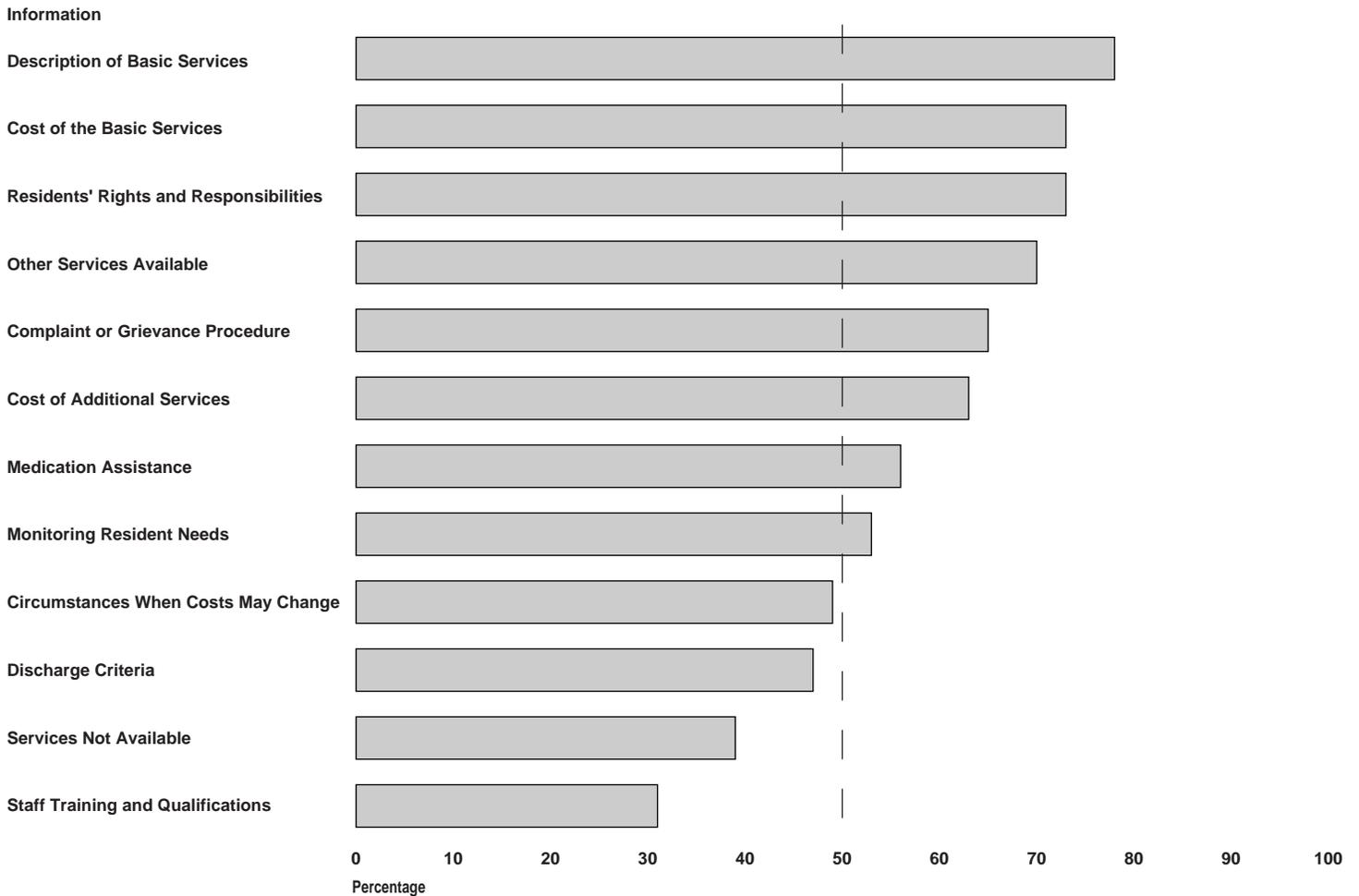
According to consumer advocates and provider associations, consumers need to be informed about the services that will be provided, their costs, and the respective obligations of both the resident and the provider. Such information should include

- the cost of the basic service package and what it includes;
- the availability of additional services, who will provide them, and their cost;
- the circumstances under which costs may change;
- how the facility monitors resident health care;
- the qualifications of staff who provide personal care, medications, and health services;
- discharge criteria, such as when a resident may be required to leave the facility, and the procedures for notifying and relocating the resident; and
- grievance procedures.

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The majority of facilities responding to our survey said they generally provide prospective residents with written information about many of their services and costs in advance of their choosing to apply for admission. However, as shown in figure 1, only about half indicated that they provide information on the circumstances under which the cost of services may change, their policy on medication assistance, or their practice for monitoring residents' needs, and less than half indicated that they provide written information in advance about discharge criteria, staff training and qualifications, or services not covered or available from the facility.

Figure 1: Percentage of Facilities Reporting That They Provide Key Written Information to Prospective Residents



The contract or resident agreement is an important source of written information, and in some cases it may be the only place where certain key points such as discharge criteria or circumstances when costs may change are addressed. However, only one out of four facilities we surveyed indicated that they routinely provide a copy of the contract to consumers before they make a decision to apply for admission. About 65 percent of the facilities said they provide a copy when one is requested, and 10 percent said they do not generally provide contracts to prospective

residents. Contracts range from a one-page standard form lease to a 55-page document with attachments. Some are written in very fine print, while others are prepared in large, easy-to-read type. Some contracts are complex documents written in specialized legal language, while others are not. Marketing and other written material provided by the facilities also vary widely from a one-page list of basic services and monthly rent to multiple documents of more than 100 pages.

We examined written marketing materials and contracts from 60 of the facilities that responded to our survey to determine whether they were complete, clear, and consistent with state laws. While most of the facility materials we reviewed were specific and relatively clear, we found that materials from 20 of the 60 facilities contained language that was unclear or potentially misleading, usually concerning the circumstances under which a resident could be required to leave a facility. Contracts and other written materials we reviewed were often unclear or inconsistent with each other or with requirements of state regulation regarding how long residents could remain as their needs change, resident notification requirements, and other procedural requirements for discharge. For example, the contract from a California facility was vague regarding the circumstances under which a resident could be required to move. It stated that the facility can discharge a resident for good and sufficient cause without elaborating on what the cause might be. The contract also failed to refer to state regulations that provide specific criteria for discharge or eviction.

As shown in figure 2, the marketing material one Florida facility uses is potentially misleading in specifying that residents can be assured that if their health changes, the facility can meet their needs and they will not have to move again. However, the facility's contract specifies a range of health-related criteria for immediate discharge, including changes in a resident's condition or need for services that the facility cannot provide. The contract of an Oregon facility is inconsistent with requirements of state regulation regarding notification of residents before discharging them. Oregon regulations specify that residents may not be asked to leave without 14 days' written notice that a facility cannot provide the services they need. However, the facility's contract specifies that residents can be required to move immediately if they need more care than is available at the facility.



similar requirements regarding the type and level of services that assisted living facilities must provide residents. In addition to basic accommodations such as room, board, and housekeeping, all the states require facilities to provide residents with basic services, including assistance with ADLs, ongoing health monitoring, and either the provision of or arrangement for medical services, including transportation to and from those services as needed.

All four states require assisted living facilities to conduct an initial assessment of a resident's health, functional ability, and needs for assistance. They also require that facilities provide residents with reasonable advance notice of discharge or eviction, and they specify certain rights and procedures for residents to appeal or contest a facility's decision to discharge them. State regulations also generally contain other consumer protection provisions such as those governing resident contracts, criminal background checks for staff, and residents' rights. All four states require that facilities enter into contracts with residents, but they differ in the level of detail they require in these agreements. In addition, all four states require criminal background checks for direct care staff, and three states—California, Florida, and Oregon—require them for facility administrators as well.

State regulations often differ, however, with respect to the level of skilled nursing or medical care that facilities can provide to residents and in the circumstances under which it can be provided. For example, California regulations contain a list of services that facility staff are generally not allowed to provide, such as catheter care, colostomy care, and injections. In contrast, Oregon has no explicit restrictions on the care that facility staff may provide, except that certain nursing tasks must be either assigned or delegated to a caregiver by a registered nurse. In addition, while all four states require facilities to provide some degree of supervision with medications, they differ in the degree to which facility staff can be directly involved in administering medications to residents. For example, in California, facility staff may not administer medications but may only assist residents to take their own medications. Requirements for staff levels, qualifications, and training also vary among the states. For example, Florida requires facilities to maintain a minimum number of full-time staff that is based on the total number of residents, California and Ohio require only that the number of staff be adequate to meet the needs of residents, and Oregon does not have any minimum staffing requirement.

To ensure that assisted living facilities comply with the various licensing requirements, all four states conduct periodic inspections or surveys of facilities, and they may also conduct more frequent inspections in response to specific complaints.<sup>6</sup> However, the four states vary in the frequency and content of assisted living facility inspections. The frequency of required licensing inspections ranges from at least twice a year for extended congregate care facilities in Florida to at least once every 2 years for assisted living facilities in Oregon.<sup>7</sup> The content of periodic state surveys is driven primarily by the requirements in state regulations. To assist surveyors, Florida and Ohio have developed detailed guidelines, similar to those used for nursing home inspections. In contrast, surveyors in California and Oregon use a checklist that covers a subset of the regulations and focuses on a few selected elements.

In addition to the state licensing agency, other state agencies play a role in the oversight of assisted living facilities. In the four states we examined, the state ombudsman agency has a role in overseeing the quality of care and consumer protection of residents in assisted living. The ombudsmen are intended to serve as advocates to protect the health, safety, welfare, and rights of elderly residents of long-term care facilities and to promote their quality of life. One of their primary responsibilities is to investigate and resolve complaints of residents in long-term care facilities, such as nursing homes, board and care homes, and assisted living facilities. Ombudsmen in Florida are also required to inspect each facility annually to evaluate the residents' quality of care and quality of life. In two of the four states, Florida and Oregon, APS agencies are responsible for investigating reports of alleged abuse, neglect, or exploitation of assisted living residents; determining their immediate risk and providing necessary emergency services; evaluating the need for and referrals for ongoing protective services; and providing ongoing protective supervision.

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<sup>6</sup>In Florida, Ohio, and Oregon, the agency with responsibility for inspecting assisted living facilities also has responsibility for nursing homes. In contrast, responsibility for the regulation and inspection of assisted living facilities in California rests with the Department of Social Services, while nursing homes fall under the jurisdiction of the Department of Health Services.

<sup>7</sup>Florida has multiple categories of assisted living licensure, including standard assisted living, limited nursing services, and extended congregate care.

## The States Identify Quality-of-Care and Consumer Protection Problems in Assisted Living Facilities

Given that the states vary in their licensing requirements for assisted living facilities and in their approaches to oversight, the type and frequency of quality-of-care and consumer protection problems identified by the states may not fully portray the care and services the facilities actually provide. Facilities in states with more licensing standards, more frequent inspections, or more agencies involved in oversight may be more likely to have more problems identified and verified. Using available data and reports from state licensing, ombudsman, and APS agencies in the four states, we determined that 27 percent of the 753 facilities in our sample were cited for five or more quality-of-care or consumer protection related problems during 1996 and 1997. Most of these verified problems pertained to quality-of-care rather than consumer protection issues. As table 1 shows, 22 percent of the facilities we sampled had 5 or more verified quality-of-care problems during the period, and 9 percent of the facilities had 10 or more.

**Table 1: Percentage of Facilities With Quality-of-Care and Consumer Protection Related Problems Identified by Licensing, Ombudsman, and APS Agencies in the Four States**

Number of problems	Facilities with verified problems		
	Quality of care or consumer protection	Quality of care	Consumer protection
5 or more	27%	22%	3%
10 or more	11	9	0

Note: Number of facilities = 753.

The most commonly cited quality-of-care problems included inadequate care, staffing, and medication issues. These problems included instances in which a facility was found to be providing inadequate care to residents as well as instances in which a facility did not demonstrate the capacity to provide sufficient care. For example, staffing problems included cases in which residents suffered harm as a result of insufficient numbers of staff in the facility, as well as cases in which facilities had no documentation to substantiate that required caregiver training had been provided.

Inadequate care, such as instances of residents not receiving appropriate access to physicians and other needed medical care or treatment, was the most frequently cited quality-of-care problem. For example, as illustrated in table 2, in one California facility, staff neglected to call “911” after a resident fell and injured her head. Instead, they gave her aspirin, and several hours later she was found in a comatose state. She died 3 days later. The second most frequently cited problem concerned staff

qualifications and training and facilities not having sufficient staff to care for the residents. For example, in an Oregon facility, family members routinely assisted residents by changing soiled garments because the facility did not have enough staff.

**Table 2: Examples of Quality-of-Care and Consumer Protection Problems**

<b>Issue</b>	<b>Problem</b>
Quality of care	
Inadequate care	Staff neglected to call "911" after a resident fell and injured her head. Instead, they gave her aspirin, and several hours later she was found in a comatose state. She died 3 days later.
Staffing	Because of insufficient staff, family members in one facility routinely assisted residents by changing soiled garments.
Medication	Facility staff inconsistently and inaccurately transcribed physicians' medication orders, often allowed sharing of medications between residents, signed out narcotics on one shift but had staff from another shift administer them, and allowed unlicensed caregivers to alter residents' prescription labels.
Consumer protection	
Billing or discharge	A resident was told on admission that she could stay in the facility until she died. After living at the facility for 2 years, she began to wander within the facility. The facility then issued a 2-week eviction notice stating that it could no longer care for her. The facility also increased her monthly fee from approximately \$1,600 to more than \$6,400. She moved to another facility.
Contracts	A resident contract did not contain all state-required elements, such as the basic daily, weekly, or monthly rate and a list of available services and fees not included in the basic rate.

The third most frequently cited problem concerned medication-related issues, such as not providing residents their prescribed medication, providing them the wrong medication, or storing medication improperly. For example, an Oregon facility was found to have numerous medication problems, including (1) staff inconsistently and inaccurately transcribing physicians' medication orders to the residents' medication administration records, (2) medications often being borrowed or shared between residents, (3) one staff member signing out narcotics but another staff member on a different shift administering them to residents, and (4) unlicensed caregivers altering residents' prescription labels.

Commonly cited consumer protection problems included those related to circumstances under which a resident could be required to leave a facility for health or financial reasons and those related to provisions in resident contracts. For example, a resident of an Oregon facility was told on admission that she could stay until she died. However, the facility issued her an eviction notice when she began to wander within the facility, and it raised her monthly charge from approximately \$1,600 to more than \$6,400. In Florida, a facility was cited for not having all state-required elements in the resident contract, such as the basic daily, weekly, or monthly rates and a list of available services and fees not included in the basic rate.

In Florida and Oregon, the two states in which APS agencies have some responsibility for oversight of residents in assisted living facilities, resident abuse was also often cited. In Oregon, the APS agency verified 48 cases of abuse in 21 of the state's 83 assisted living facilities during 1996 and 1997. In one case, a resident was left on the toilet for 2 hours because the caregiver forgot to return to the resident's room, and there was no call button within reach. In Florida, the APS agency verified 39 cases of abuse in 25 facilities and 103 cases of neglect in 32 facilities during the 2-year period. Florida cases included an instance in which a 90-year-old resident was admitted to a hospital with a stage IV pressure ulcer and found to be dehydrated and poorly nourished.

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## Conclusions

As a growing number of elderly Americans reach the point where they can no longer live independently, many look to assisted living facilities as a viable, homelike setting to meet their long-term care needs. While many residents may enter assisted living facilities with relatively few or minimal needs for supportive or health services, these needs generally increase with age or with declining health. Some assisted living facilities may be able to accommodate these changing and more intensive needs, while others may not. Fully understanding the strengths and limitations of facilities is important as consumers and their families attempt to make the best choice for what is often a difficult decision.

Currently, the assisted living industry is predominantly funded by private resources and is licensed and regulated by the states. However, as the states increase their use of Medicaid to help pay for assisted living, the contribution of federal financing will grow as well. This trend will no doubt focus more attention from consumers, providers, and the public sector on several issues, including where assisted living fits on the continuum of long-term care, on standards needed to ensure quality of

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care and protect consumers, on appropriate approaches to ensure compliance with those standards, and on the adequacy of information available to help inform consumers' choices and decisions.

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Mr. Chairman, this concludes my statement. I will be happy to answer any questions that you or other members of the Committee may have.

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