

April 2004

ASSISTED LIVING

Examples of State Efforts to Improve Consumer Protections





Highlights of [GAO-04-684](#), a report to congressional requesters

Why GAO Did This Study

Assisted living facilities provide help with activities of daily living in a residential setting for individuals who cannot live independently but do not require 24-hour skilled nursing care. In 2002, over 36,000 assisted living facilities served approximately 900,000 residents. The states establish and enforce licensing standards for these institutions. Because states have taken widely differing approaches to regulating and supporting assisted living, they can potentially learn from each other's experiences as they consider changes to their own policies.

GAO was asked to review challenges faced by consumers and providers of assisted living and seek out notable state initiatives addressing those challenges in three selected areas: (1) disclosure of full and accurate information to consumers, (2) state assistance to providers to meet licensing requirements, and (3) procedures for addressing residents' complaints. We identified specific examples of individual programs in Florida, Texas, Washington, Georgia, and Massachusetts that highlighted different approaches in these three areas, which other states might wish to consider emulating.

www.gao.gov/cgi-bin/getrpt?GAO-04-684.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Leslie G. Aronovitz at (312) 220-7600.

ASSISTED LIVING

Examples of State Efforts to Improve Consumer Protections

What GAO Found

Consumers faced with choosing an assisted living facility often do not have key information they need in order to identify the one most likely to meet their individual needs. Such information includes staffing levels and qualifications, costs and potential cost increases, and the circumstances that could lead to involuntary discharge from the facility. Initiatives in Florida and Texas have made critical data for consumer selection among facilities more readily available. Florida has created a Web site that enables consumers to learn about all of the facilities in their vicinity and identifies those providing the services the consumers are seeking at a specified price range. Texas has mandated a standardized disclosure statement for assisted living facilities, giving consumers concise and consistent data that facilitates comparisons across providers regarding services, charges, and policies.

Assisted living facilities are more likely to meet and maintain licensing standards if they can obtain help in interpreting those standards and in determining what concrete changes they need to make to satisfy them. Washington State established a staff of quality consultants to provide such training and advice to assisted living providers on a voluntary basis. Evaluations of the program 6 months after its start and 2 years later documented improvements in provider compliance as well as resident health and safety. However, a statewide budget crisis led to a decision to stop funding the program, in order to maintain traditional licensing enforcement functions.

Assisted living residents sometimes need help to pursue any complaints that they may have with their providers, especially when faced with an involuntary discharge. Long-term care ombudsmen are available in all states, but nursing home residents claim most of their attention. Georgia has legislated an extensive array of procedural remedies specifically for assisted living residents that provide them multiple means for seeking redress of their complaints. The existence of these remedies also strengthens the position of residents in the informal negotiations through which most such disputes are resolved in practice. Massachusetts has created a small staff of ombudsmen dedicated exclusively to serving assisted living residents. This allows them to specialize in addressing the particular problems that arise in assisted living facilities.

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Abbreviations

ADL	activities of daily living
DOEA	Florida Department of Elder Affairs
DSHS	Washington Department of Social and Health Services
EOEA	Massachusetts Executive Office of Elder Affairs
ORS	Georgia Office of Regulatory Services
OSAH	Georgia Office of State Administrative Hearings
QIC	Washington Quality Improvement Consultation Program

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United States General Accounting Office
Washington, DC 20548

April 30, 2004

The Honorable Larry E. Craig
Chairman
The Honorable John B. Breaux
Ranking Minority Member
Special Committee on Aging
United States Senate

The Honorable Ron Wyden
United States Senate

A growing number of elderly Americans who can no longer live independently have turned to assisted living as an alternative to nursing homes. Assisted living facilities provide help with activities of daily living (ADL) in a residential setting for individuals who do not require 24-hour skilled nursing care. In 2002, over 36,000 assisted living facilities served approximately 900,000 residents. In contrast to nursing homes, with their extensive federal rules and mandates, the federal government exercises minimal oversight of assisted living facilities. The states establish and enforce licensing standards for these institutions.

For a number of years, the Senate Special Committee on Aging has monitored developments in the assisted living industry. In 2001, the committee asked a broad-based group of stakeholders to form a committee, known as the Assisted Living Workgroup, to develop recommendations that could help states and other entities ensure the quality of assisted living services across the country. The Workgroup issued its report in April 2003. It contained 110 specific recommendations covering a wide range of topics, each supported by two thirds or more of the 48 participating organizations. These recommendations included proposals to enhance the information provided to potential residents as they choose among assisted living facilities, to have states consider offering providers technical assistance to address state licensing standards, and to expand federal and state support for assisted living residents who have complaints about their facilities.

Subsequently, you asked us to review state efforts in these three selected areas: (1) disclosure of full and accurate information to consumers, (2) state assistance to providers to meet licensing requirements, and (3) procedures for addressing residents' complaints.¹ As you requested, we agreed to examine the challenges faced by consumers as well as providers in these three areas and then seek out notable state initiatives intended to address these issues, outlining for each selected program or policy its main features, intended benefits, and perceived effectiveness.

In addressing these objectives, we interviewed experts from academia and selected assisted living organizations representing for-profit and nonprofit providers, consumer advocates, and state regulators. (See app. I.) Working largely with the information obtained from these interviews, combined with available research and evaluations on assisted living and guides to applicable state regulations, we chose five specific initiatives from Florida, Texas, Washington, Georgia, and Massachusetts to highlight. We based this selection on evidence that the chosen program or policy in that state differed in defined ways from approaches typically taken by other states. We did not undertake a formal evaluation of these programs or policies, nor did we systematically compare them with alternative approaches adopted in other states. For each of the selected initiatives, we conducted additional interviews with responsible state officials as well as representatives of providers and consumers in that state. We also drew on any relevant studies, tracking data, or related public documents. We reviewed relevant laws and regulations in the five states with initiatives selected for study. References to assisted living laws and regulations in all other states are based on secondary sources. We performed this work from November 2003 through April 2004 in accordance with generally accepted government auditing standards.

Results in Brief

Consumers faced with choosing an assisted living facility often do not have key information they need in order to identify the one most likely to meet their individual needs. Such information includes staffing levels and qualifications, costs and potential cost increases, and the circumstances that could lead to involuntary discharge from the facility. Initiatives in Florida and Texas have made critical data for selection among facilities more readily available to prospective assisted living residents. Florida has

¹In this report, we use the term "complaint procedure" to encompass state policies that refer to either complaints or grievances.

created a Web site that enables consumers to learn about all of the facilities in their vicinity and identifies those providing the services the consumers are seeking in a specified price range. Texas has mandated a standardized disclosure statement for assisted living facilities, giving consumers concise and consistent data that facilitate comparisons across providers regarding services, charges, and policies.

Assisted living facilities are more likely to meet and maintain licensing standards if they can obtain help in interpreting those standards and in determining what concrete changes they need to make to satisfy them. Washington State established a staff of quality consultants to provide such training and advice to assisted living providers on a voluntary basis. Evaluations of the program 6 months after its start and 2 years later documented improvements in provider compliance as well as resident health and safety. However, a statewide budget crisis led to a decision to stop funding the program, in order to maintain traditional licensing enforcement functions.

Assisted living residents sometimes need help pursuing any complaints that they may have with their providers, especially when faced with an involuntary discharge. Long-term care ombudsmen are available in all states, but nursing home residents claim most of their attention. Georgia has legislated an extensive array of procedural remedies specifically for assisted living residents that provide them multiple means for seeking redress of their complaints. The existence of these remedies also strengthens the position of residents in the informal negotiations through which most such disputes are resolved in practice. Massachusetts has created a small staff of ombudsmen dedicated exclusively to serving assisted living residents. This allows them to enhance their expertise in addressing the particular problems that arise in assisted living facilities.

Background

Over the last decade, assisted living has emerged as an increasingly popular long-term care option. Within the continuum of long-term care, assisted living facilities typically provide a level of care between independent living and nursing homes for persons who need assistance with one or more ADLs, such as bathing or dressing.² However, states vary

²Independent living facilities generally provide elderly people a residential setting that offers meals, housekeeping, laundry, transportation, and social and recreational activities, according to the American Seniors Housing Association. These facilities do not provide personal care or health services.

in the term they use for assisted living—it appears in the licensing regulations of most states but some refer instead to personal care homes, boarding homes, residential care facilities, adult homes, and homes for the aged³—and in the characteristics of the facilities encompassed by the term used. A 2002 study of assisted living policies in each of the 50 states and the District of Columbia showed that states differ in the facilities included under their assisted living regulations based on facility size, services provided, and whether or not the facilities offer specified types of accommodations such as private apartments.⁴ In addition, the study found that many states incorporate a distinctive philosophy of care in their regulation of assisted living facilities to emphasize residents' choice, independence, dignity, and privacy. Specifically, 28 states have included an assisted living philosophy statement in their regulations, but specifics of the statements vary.

Unlike nursing homes, which are subject to extensive federal regulations, assisted living facilities generally have considerable flexibility to determine the resident populations that they serve and the services they provide. As a result, assisted living facilities vary widely on both of these dimensions. Nevertheless, most facilities provide housing, meals, housekeeping, laundry, supervision, and assistance with some ADLs and other needs, such as medication administration. The majority of assisted living residents are between the ages of 75 and 85 and more than two thirds are females. About a quarter of assisted living residents need help with three or more ADLs.⁵ Eighty-six percent of residents require or accept help with medication.⁶ Facilities differ in the extent to which they admit residents with certain needs (including residents who meet the criteria for admission to nursing homes) and whether they retain residents as their

³American Seniors Housing Association, *Seniors Housing: State Regulatory Handbook*, (Washington, D.C.: March 2003). Thirty-three states and the District of Columbia refer to assisted living in their licensing regulations.

⁴Robert Mollica, *State Assisted Living Policy: 2002* (Portland, Me.: National Academy for State Health Policy, November 2002).

⁵In contrast, among nursing home residents, about 83 percent require assistance with three or more ADLs. Catherine Hawes et al., *A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities* (Beachwood, Ohio: December 1999), Prepared for the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.

⁶Residents need differing levels of assistance with medication, such as supervision of self-medication or medicine storage and dispensing. National Center for Assisted Living, *Assisted Living: Independence, Choice, and Dignity* (March 2001).

needs change. For example, a 2000 study found that less than half of the assisted living facilities are willing to admit or retain persons who require assistance to transfer from bed to chair or wheelchair.⁷ This study also found that less than half of the facilities would admit or retain residents with moderate to severe cognitive problems.⁸

The type, size, and cost of assisted living facilities also vary widely. Some facilities are freestanding while others are located on a campus that contains multiple units offering different levels of care (such as nursing homes and independent living residences). Those built in the 1980s generally provide semiprivate accommodation while the newer facilities typically offer private apartments. Facilities range in size from a few beds to over a thousand. The average facility in a nationwide study had 53 beds.⁹ Many facilities are independently owned while others belong to regional or national chain corporations. Assisted living fees vary widely across and within states depending on the facility's size, service, and location. For example, the average monthly base rate ranged from \$1,020 in Mississippi to \$4,429 in Washington, D.C., according to a recent industry survey.¹⁰ Residents often pay additional fees for special care units and other services, such as medication administration and transportation. Two thirds of assisted living residents pay out-of-pocket, but many states use

⁷Catherine Hawes et al., *A National Study of Assisted Living for the Frail Elderly: Final Summary Report* (Beachwood, Ohio: November 2000), Prepared for the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services.

⁸The Alzheimer's Association concluded from the most recent available research that at least half of elderly assisted living residents have some degree of cognitive impairment, though most of them do not live in specialized dementia care units. The Association based its estimate of the prevalence of cognitive impairment on state and national studies conducted between 1997 and 2002. See Alzheimer's Association, *People with Alzheimer's Disease and Dementia in Assisted Living* (Advocacy and Public Policy Division) Aug. 13, 2003; Alzheimer's Association, *Special Care Units in Assisted Living*, (Public Policy Division) August 2003.

⁹Catherine Hawes et al., *A National Study of Assisted Living for the Frail Elderly: Results of A National Survey of Facilities*, (Beachwood, Ohio: December 1999).

¹⁰The *MetLife Market Survey of Assisted Living Costs*, MetLife October 2003. LifeCare Inc. conducted this survey for MetLife. It was not based on a representative national sample, though it included 87 major markets in all 50 states and the District of Columbia. According to this survey, the national average monthly base rate for an assisted living facility resident in the United States is \$2,379 (\$28,548 per year).

Medicaid and other federal and state funds to help finance such care.¹¹ As of October 2002, 41 states used Medicaid reimbursement to cover assisted living or related services for more than 102,000 people.¹²

The federal government exercises minimal oversight over assisted living, leaving to the states primary responsibility for ensuring that assisted living residents have adequate protections.¹³ Some states fulfill this responsibility by establishing licensing standards, inspection procedures, and enforcement measures. Nevertheless, the regulatory approaches to assisted living adopted by states vary widely in scope and structure. For example, some states delineate the services that assisted living facilities may or may not provide—sometimes with multiple tiers of licenses for more specialized care—while others grant broad flexibility to providers to meet the individual needs of residents and their families.¹⁴ All states have long-term care ombudsmen with potential jurisdiction over assisted living facilities. Among other things, ombudsmen may provide services to protect assisted living residents and resolve complaints that they file. Ombudsmen may monitor quality of care, educate residents about their rights, and mediate disputes between residents and providers.

¹¹*Assisted Living: Independence, Choice, and Dignity*, National Center for Assisted Living (March 2001). To help pay for assisted living services such as personal care and homemaker services, states typically use Medicaid waivers, specifically the Home and Community Based Services Waiver. These waiver payments do not cover room and board. States have considerable flexibility in determining the type of services and recipients covered under these waivers with limited reporting requirements to the federal government. For details on reporting requirements, see U.S. General Accounting Office, *Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should be Strengthened*, [GAO-03-576](#) (Washington, D.C.: June 20, 2003).

¹²Robert Mollica, *State Assisted Living Policy: 2002* (Portland, Maine: National Academy for State Health Policy, November 2002).

¹³Although a number of federal agencies have jurisdiction over certain aspects of consumer protection and quality of care in assisted living, few federal standards or guidelines specifically govern assisted living. In general, the role of federal agencies in this area is to administer laws that relate to the funding of certain programs, such as Medicaid reimbursement for the direct care services component of assisted living and funding the state-run long-term care ombudsmen program. The federal government grants broad discretion to the states in carrying out their oversight responsibilities. For further details see U.S. General Accounting Office, *Long-Term Care: Consumer Protection and Quality-of-Care Issues in Assisted Living*, [GAO/HEHS-97-93](#) (Washington, D.C.: May 15, 1997).

¹⁴Robert Mollica, et al, *State Assisted Living Practices and Options: A Guide for State Policy Makers*, (Washington, D.C.: Development Corporation: September 2001).

Prior GAO reports have addressed a number of consumer protection and quality of care issues that remain at the forefront of public concerns about assisted living.¹⁵ These reports raised questions about the adequacy of information available to prospective consumers to help them choose a facility that meets their needs. The 1999 report also discussed states' varying approaches to oversight and the type and frequency of consumer protection and quality of care problems that state agencies identified.

State Efforts to Enhance Consumer Information on Facility Options

Given the wide diversity among assisted living facilities in the services they offer and the populations they are prepared to serve, prospective assisted living residents can have difficulty finding an appropriate—let alone the most appropriate—facility to meet their individual needs. Initiatives such as the Florida “Find-a-Facility” Web site and the Texas standardized disclosure statement help consumers make better choices by providing them the information they need in an easier-to-absorb format.

Consumers Often Lack Key Information to Make Appropriate Choices

Available studies and interviews with our experts indicate that consumers choosing among their assisted living options often lack the information they need to make a fully informed selection. The limitations in the information currently provided to consumers relate to both its substantive content and mode of presentation. To make appropriate choices among the wide range of facility options available in the market, consumers need to learn about facility services, costs, and policies that impact residents. Moreover, they need this information to be not only complete and accurate, but also presented in a timely way and in a form that they can understand. When consumers do not receive adequate information before selecting an assisted living facility, they are less likely to find a facility that can satisfactorily address their personal care needs.

In making selection decisions, consumers rely on facility information that they receive in various ways, including marketing brochures, facility tours, and interviews with providers. Consumers also rely on the advice of family, friends, or health care professionals. Our 1999 report stated that marketing materials, contracts, and other written materials that facilities give consumers were often vague, incomplete, or misleading. Specifically,

¹⁵U.S. General Accounting Office, *Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States*, [GAO/HEHS-99-27](#) (Washington, D.C.: Apr. 26, 1999) and [GAO/HEHS-97-93](#).

the report found that facilities' written materials often did not contain key information, such as a description of services not covered or available at the facility, the staff's qualifications and training, circumstances under which costs might change, assistance residents would receive with medication administration, facility practices in assessing needs, or criteria for discharging residents if their health changes. Subsequent studies, including the 2003 Workgroup report, as well as experts that we interviewed, indicate that consumers continue to have difficulty obtaining full disclosure of the information they need.¹⁶ In response to this deficiency, 18 states have instituted information disclosure policies, such as requirements on the use of uniform disclosure statements or the contents of written materials provided to prospective residents.¹⁷

Our expert interviews and the studies we reviewed identified information about staffing levels and qualifications, costs and potential cost increases, and facility policies regarding discharge criteria as critical to informed decision making. Consumers need to know, for example, whether a facility has staff to provide full 24-hour service to address recurring care needs, such as assistance administering medications, as distinct from a facility whose overnight staff is only available to deal with emergency situations. While some facilities reportedly disclose only aggregate staffing data, the most important information for consumers concerns the number of staff directly involved in providing care to residents. Expert interviews and reviewed studies also indicated that consumers do not always receive information clearly explaining the circumstances under which resident costs can increase. Similarly, according to a consumer advocate organization, providers do not always inform consumers about the circumstances under which they could be involuntarily discharged from their facility, even when state regulations dictate that residents must leave if their needs reach a certain level.

The experts we interviewed underscored the importance of conveying critical information about assisted living choices in a way that consumers can readily absorb. The experts explained that prospective residents and

¹⁶*White Paper on Assisted Living*, National Academy of Elder Law Attorneys, Inc. (Tucson, Az.: 2001). Deanna Okrent and Virginia Dize, *Ombudsman Advocacy Challenges in Assisted Living: Outreach and Discharge* (Washington, D.C., National Association of State Units on Aging: March 2001).

¹⁷See *State Assisted Living Policy: 2002* (Portland, Maine: National Academy for State Health Policy, November 2002), section 1.5.

family members often have difficulty grasping the information presented to them, especially when they have to make decisions quickly to address a crisis situation. Under these circumstances, consumers often do not know what questions to ask or how to assess and compare the responses that they receive in order to identify the facility that can best meet their individual needs.

When consumers do not get complete and accurate information on the assisted living alternatives available to them, in a form that they can understand, they run the risk of choosing a facility that cannot adequately meet their personal care requirements. A likely consequence is that they will have to move again within a short time. Both consumers and providers benefit if they can minimize this risk by ensuring that the consumer has, and can use, the critical information relevant to making an informed choice among different facilities.

Florida Sponsors an Internet-based Facility Locator

In the summer of 2003, Florida's Department of Elder Affairs (DOEA) launched its Affordable Assisted Living Web site to enhance public access to information on assisted living.¹⁸ One of its features is called "Find-a-Facility," a search tool that allows anyone with internet access to identify those Florida assisted living facilities that match the preferences set by the user. The available options include geographic location, price range, housing configurations (such as private apartments), whether the facility accepts residents with government subsidies or certain disabilities, and clinical and social services offered. (For examples of the Web site pages, see app. II.) Once the user selects his preferences among the available options, the site generates a list of licensed facilities, with those most closely matching the chosen preferences ranked highest. For each of these facilities, the user can print out a one-page description that includes the facility's contact information, number of beds, specific government subsidy programs it participates in, any specialized care licenses, and all of its entries on the list of selection options.

Development of the Web site occurred through a collaboration of public and private entities. It began under Florida's Coming Home Program, sponsored by the Robert Wood Johnson Foundation. DOEA established a committee comprised of representatives of providers, consumers, and regulators. They found a need for a comprehensive information

¹⁸Found at www.floridaaffordableassistedliving.org.

clearinghouse to inform both providers and consumers about assisted living options and the multiple long-term care and housing assistance programs designed to make these options more widely available. The “Find-a-Facility” feature developed from discussions with social workers and case managers who had helped elderly clients find appropriate assisted living residences. They underlined the need to identify the facilities that met their clients’ needs and preferences and that the clients could afford, often with the assistance of government subsidies. Many had been relying on placement agencies, which would only list facilities that had paid the agency a fee. Larger, more expensive, private pay facilities were more likely to sign on with the placement agencies, meaning that prospective residents were less likely to find out about smaller, less expensive, or subsidized facilities in their area.

Several state agencies then joined together in the technical development of the Web site. Specifically, DOEA, the Florida Agency for Health Care Administration, and the Florida Housing Financing Corporation contributed staff time and services, in addition to state funding of about \$29,000. The state tested the prototype site for several months with different consumer groups, such as Alzheimer caregivers and visitors to neighborhood senior centers. Based on the feedback received, state officials made further refinements in the wording of entries, their organization, and the instructions provided to users. DOEA subsequently developed a Spanish-language version of the site, which came into operation in April 2004.

To promote the Web site, the state informed providers and potential residents of assisted living facilities about the site and how to use it. DOEA took care to contact professionals who typically help place residents in assisted living, distributing brochures to social workers and hospital discharge planners as well as local area agencies on aging. Consumer advocacy groups such as AARP and the Alzheimer’s Association were also encouraged to help get the word out about the Web site. Usage rates have increased steadily, reaching about 250 visitors a day by February 2004.

DOEA also provided training to assisted living providers, to help them enter much of the data presented on the Web site. All licensed facilities are included in the basic database, with information on facility location, number of beds, state licenses held, and contact information downloaded from Agency for Health Care Administration files. However, providers

voluntarily enter virtually all of the descriptive information on price range, housing configurations, populations served, and services offered.¹⁹ A provider representative indicated that entering the Web site data initially takes 10 to 15 minutes. Providers can update their information at any time. By February 2004, approximately 40 percent of assisted living facilities had filled in their data fields. DOEA receives about two inquiries a week from providers asking for assistance, but in general the providers find this process relatively easy. Initial skepticism among some providers has diminished as they hear from providers already in the system and they recognize the inherent advantage of free advertising. This is especially beneficial for smaller, independent facilities that cannot match the commercial advertising of the national and regional chains.

A state administrator noted that maintenance of the Web site requires some continuing effort. With substantial turnover among facility providers and professionals assisting prospective residents, outreach and training is an ongoing process. DOEA also tries to spot-check at least some key data elements entered into the system, even though the Web site itself prominently displays a disclaimer that provider-entered data have not been verified for accuracy.

No formal evaluations of the Web site have yet been undertaken, but informal feedback has been uniformly positive according to both provider and consumer representatives, as well as the state official responsible for its operation. Consumers, and those acting on their behalf, are finding that the Web site has several distinct advantages over previously available information sources. Most importantly, it provides a way to efficiently narrow their search. They can quickly identify the universe of facilities within a given area and determine which offer the services they are looking for at a price they can afford. Current information about participation in government subsidy programs is especially valuable for many prospective residents of limited means. In addition, because “Find-a-Facility” is on the internet, out-of-state family members can actively participate in the process of locating an appropriate facility. Similarly, the Web site makes it much easier for professionals assisting elderly clients, such as social workers and hospital discharge planners, to determine the full list of available placement options.

¹⁹ DOEA is working to facilitate provider access to the internet. It has helped that a substantial number of assisted living facilities already had acquired internet access in response to earlier state incentives for submitting Medicaid bills electronically.

Texas Requires Facilities to Distribute Standardized Disclosure Statements

In 1999, Texas enacted a law requiring assisted living facilities to provide each prospective resident a consumer disclosure statement that follows a standard format approved by the Department of Human Services.²⁰ Its purpose is to enable consumers to better compare facilities by describing their policies and services in terms of uniform categories. However, its effectiveness depends not only on its content but also on how and when facilities distribute it to consumers.

This five-page checklist form addresses many of the topics identified in our expert interviews as critical for consumers choosing among alternative assisted living facilities. It describes the services and amenities provided to all residents, as well as those offered at additional cost. (See app. III.) The form also lists circumstances that could lead a resident to be discharged from the facility and the training received by staff. It includes a chart showing the number and type of staff on duty for each daily shift, which is also posted in public view at the facility.

While a number of other states have developed similar forms—particularly for specialized dementia units—Texas is notable for having been among the first to develop a standardized disclosure statement for all assisted living facilities, and to include detailed information on staffing levels. The standardized response categories specified by the form make the furnished information consistent across facilities, allowing consumers to make comparisons more readily among them. The checklist format means that consumers see what services the facility does not provide as well as those it does. There is one version of the form for assisted living facilities in general and another, covering many of the same topics, adapted specifically for units specializing in dementia care. Neither form, though, has been translated into any languages other than English.

State officials described the process of developing these forms as proactive on their part—rather than in response to external complaints—and relatively uncontroversial. The disclosure statement for specialized dementia units emerged from a state-organized advisory committee including provider and consumer advocates. That served as the model for the more generic assisted living form issued by the department shortly thereafter. Since then, according to both state officials and an official of a state provider association, providers have accepted both forms without complaint. State officials believe that this extensive involvement of

²⁰1999 Tex. Gen. Laws ch. 233 §1 (Tex. Health & Safety § 247.026 (2003)).

providers, along with consumer representatives, in the development of the form, contributed greatly to its wide acceptance among providers as a whole.

Providers vary considerably in the way they distribute the form. Some send it out to people making phone inquiries, some provide it when prospective residents or their family members visit the facility, and some wait to distribute it when the contract is signed. Although the form states that copies should be provided to anyone who requests information about the facility, providers are only held accountable for ensuring that those who ultimately become residents in their facility received the completed form by the time they were admitted. According to the consumer representative we interviewed, residents who obtain the disclosure statement during the admissions process often pay little attention to it given all the other papers they receive and sign at that time.

Once instituted, the Texas disclosure form has imposed few burdens on either assisted living providers or state officials. According to the provider association official we interviewed, it takes no more than 20 to 30 minutes to complete. The biggest challenge is remembering to revise affected entries on the form when a facility changes its services or staffing patterns. Such revisions happen perhaps four or five times a year, on average. To meet regulatory requirements, providers need to document that residents have seen the form prior to their admission.²¹ As part of their annual inspection of licensed assisted living facilities, state inspectors can assess whether a facility has a form ready to distribute and that current residents received the disclosure form before signing their residence agreement. However, the inspection process does not include an explicit examination of the accuracy of the information provided on the form.

Available evidence suggests that the assisted living disclosure statement provides useful information to prospective residents, though it does have certain limitations. None of the state, provider, or consumer representatives we spoke with knew of any formal studies conducted on the effectiveness of the form in enhancing consumer decision making on assisted living facilities. However, the anecdotal evidence they conveyed was largely positive. The consumer and provider representatives we spoke with generally thought that the form was clear and covered the major topics that consumers need to know about. Nonetheless, the consumer

²¹40 Tex. Admin. Code § 92.41(d).

representative indicated that some residents and their families still encountered “surprises” after the resident was admitted. These typically involved the conditions under which residents could be discharged or aggregate charges assessed. According to this representative, such misunderstandings reflected, in part, the intrinsically subjective nature of certain decisions, such as whether a facility could continue to meet the needs of a resident whose level of disability may have increased over time. The provider official we interviewed suggested that the form itself could be revised to more clearly convey how increases in services used would affect the resident’s total charges.

The Texas disclosure form addresses several challenges that consumers of assisted living can face. The categories of information provided on the form help to describe for consumers, who often know little about the industry and may need to make a decision quickly, what facilities can and cannot do for their residents. They also highlight important issues, such as the facility’s discharge criteria, that prospective residents and their families should pay attention to in making their selection. In addition, having comparable information in a concise format for multiple facilities should make it easier to identify key differences among the facilities under consideration. However, these benefits depend on when the residents or their representatives receive the form. If facilities do not distribute the form to consumers until they sign a contract, it cannot help them in deciding among available facilities.

State Efforts to Facilitate Provider Compliance with Licensing Requirements

Assisted living providers may fall short of meeting state licensing standards in part because they lack a full understanding of what the standards require and how to meet them. The experience of Washington State, which for 2 ½ years employed a staff of consultants to advise and train assisted living providers, shows the potential benefits of licensing assistance programs in improved provider compliance and resident outcomes, as well as the challenge of sustaining them over time.

Providers Are Sometimes Uncertain about Regulatory Requirements

Regulations that address consumer protection and quality of care generally cover such areas as admission and discharge criteria, services and level of care provided, staffing levels and staff training, safety and health standards, and resident rights.²² To examine regulatory compliance, states periodically conduct inspections of assisted living facilities. To ensure that facilities correct their deficiencies, states may require the facility to prepare a written plan of correction. In addition, states may conduct reinspections and impose financial penalties, license revocations, and criminal sanctions. Generally, when deficiencies are found, the facility has an opportunity to correct them. However, regulatory agencies expect providers to determine how to accomplish this, drawing on outside technical advice, if needed, to resolve the issue. According to experts we interviewed, state agencies face the challenge of inspecting a rapidly increasing number of assisted living facilities with limited resources. While national data are not available, a number of inspection reports and media articles indicate that typical problems relate to inadequate care, inappropriate discharges, insufficient staffing and training deficiencies, improper drug storage or errors dispensing medications, and other safety issues.²³

One way to facilitate compliance with licensing regulations is to help providers achieve a better understanding of what the regulations actually require. The experts that we interviewed stated that providers often express confusion about actions they need to take to meet state policy or regulatory requirements. They noted that providers perceive ambiguities in regulations that can lead to inconsistent interpretations among different facility managers as well as individual state inspectors. Moreover, the rapid industry expansion has brought many new providers into the assisted living industry whose administrators may not fully understand what they need to do to meet regulatory requirements. Experts also said that uncertainties about state requirements could have negative effects on

²²American Seniors Housing Association, *Seniors Housing: State Regulatory Handbook* (Washington, D.C.: March 2003); Robert Mollica, *State Assisted Living Policy: 2002* (Portland, Maine: National Academy for State Health Policy, November 2002) Section III; Stephanie Edelstein and Karen Gaddy, *Assisted Living: Summary of State Statutes* (Washington, D.C., AARP Public Policy Institute: 2000).

²³Florida Agency for Health Care Administration, *Nursing Home and Assisted Living Facility: Adverse Incidents & Notices of Intent Filed*, Report to the Legislature May 2003 Status Report published in June 2003; Texas Department of Human Services, *Fiscal Year 2003: Long Term Care Regulatory Annual Report*, November 2003; American Bar Association, *Assisted Living: Federal and State Options for Affordability, Quality of Care, and Consumer Protection*, Bifocal Vol. 23. No. 1, Fall 2001; [GAO/HEHS-99-27](#).

consumers. For example, confusion about state rules could induce some providers to drop out of the market, which might lead to access problems in some areas, particularly in rural communities that tend to have fewer assisted living providers to begin with.

According to experts we interviewed, state licensing agencies or other entities can help providers understand regulations by providing guidance and training. Licensing assistance can take various forms, including informal phone conversations, on-site consultation and technical advice, or training courses. Such assistance may be especially critical for administrators who are new or relatively inexperienced in the assisted living industry. Even for established managers, helping them to keep their facilities in compliance with regulatory requirements benefits consumers by preventing potentially serious health and safety problems. While many experts we interviewed noted the value of combining such assistance with traditional regulatory enforcement measures, not all agreed that state agencies should provide it. Several noted that industry associations could also furnish this kind of support for their members. Moreover, representatives from one advocacy organization argued that efforts by licensing agencies to provide technical assistance to providers could draw scarce resources away from their primary responsibility of enforcing state licensing standards.

Washington Employed Consultants to Assist Providers with State Licensing Requirements

Washington enacted a law in 1997 to establish a consultative approach to help assisted living providers meet state licensing requirements.²⁴ In 2000, the state put this approach into operation with the Quality Improvement Consultation (QIC) program, which created a staff of consultants within the state's Department of Social and Health Services (DSHS) to provide training and advice to individual providers. The staff of nine regionally based consultants conducted site visits, led training sessions, and responded to telephone inquiries from assisted living providers throughout the state. These activities continued for 2 ½ years until, in the midst of a state budget crisis, the state stopped funding the program.

The QIC program came about in response to provider concerns about a major structural reorganization in the state's regulation of assisted living. In 1995, the state moved licensing and oversight responsibility for assisted

²⁴1997 Wash. Laws c. 392 § 213 (Wash. Rev. Code § 18.20.115 (2003)). In Washington, "assisted living facilities" are referred to as "boarding homes."

living from the Department of Health to DSHS. Because DSHS also had enforcement authority over nursing homes, providers anticipated that the state would approach assisted living regulation as it had nursing home oversight and lobbied for a more consultative approach. The state legislature responded by requiring DSHS, within available funding, to develop the QIC program. DSHS expected the program to enhance provider and resident satisfaction, improve resident safety and quality of care, and prevent compliance problems.

A quality improvement advisory group consisting of representatives of providers, consumers, and the state came together to develop the QIC program. Most of the group's discussion revolved around the meaning of "consultation." Provider and consumer representatives differed on whether providers could be required to participate in the program. Providers insisted that the program be entirely voluntary, while some ombudsmen believed that the providers most in need of help might be least likely to ask for it.²⁵ Provider representatives also expressed concern about the relationship of the consultants with the DSHS inspectors who enforced the state's licensing regulations. In particular, they worried that inspectors could have access to private information that providers had shared with a consultant, leading to enforcement actions rather than assistance. In addition, they wanted to prevent such information from appearing in public records.

After much discussion, the group reached consensus to make the QIC program voluntary and to define the consultants as adjuncts to, but separate from, the licensing enforcement process. The consultants would not forward information to inspectors unless they identified a situation involving immediate harm to residents. In addition, information obtained from providers would not be released publicly except in aggregated form. The state hired nine quality improvement consultants who had extensive education and experience in quality improvement, training, and consultation in the assisted living industry. The consultants conducted onsite facility visits initiated by providers in order to help them develop and implement quality improvement plans that addressed identified needs. They also led regional provider training and were available by telephone to respond to provider inquiries.

²⁵Washington providers specifically rejected the model of a technical assistance program that would authorize state licensing inspectors to refer facilities for consultation on a specified topic.

Two evaluations of the QIC program indicated overall positive results in meeting its goals.²⁶ The first evaluation took place 6 months into the program. It measured effectiveness through analysis of resident outcomes and responses to satisfaction questionnaires completed by residents, ombudsmen, providers, facility staff, and consultants. The second evaluation occurred 2 years later. It assessed provider compliance with licensing regulations and satisfaction levels among providers and ombudsmen who participated in the onsite portion of the program.

After 6 months of operation, about 82 percent of providers voluntarily participated in the QIC program in some way.²⁷ Moreover, in both evaluations, a large majority of participating providers expressed satisfaction with the QIC program. Over 90 percent of those providers indicated in the first evaluation that the program had effectively assisted them with compliance. Although this level of satisfaction declined slightly to about 79 percent 2 years later, providers indicated in the second evaluation that consultation in a voluntary, mutually respectful, and collegial manner was the program's most beneficial component.

Assisted living residents also reported positive outcomes from the program. In the first evaluation, 90 percent of residents expressed satisfaction with the results of the program's on-site visits. Among those residents assessed by consultants on more than one visit, 86 percent showed improvement in identified areas of concern. These areas involved a variety of quality of care issues, including administration of medications and ADL assistance. Similarly, with respect to safety issues, 65 percent of the residents seen on more than one visit demonstrated improvement in areas such as prevention of falls.

Finally, both providers and the state attributed improvements in regulatory compliance partly to the work of the QIC program. The second evaluation included an analysis of statewide provider compliance prior to (1998 to 2000) and after implementation (2001 to 2002) of the QIC program. Although there was a slight increase in the number of state

²⁶Alice Mahar Dupler; Neva L Crogan; Robert Short, "Pathways to quality improvement for boarding homes: A Washington state model," *Journal of Nursing Care Quality*; Jul 2001; 15(4), 1-7; Alice Mahar Dupler, "Quality Improvement Consultation Program in Assisted Living Facilities, A Washington State Pilot Program: Phase II," unpublished, no date.

²⁷Among all the state's assisted living facilities, 25 percent engaged in on-site visits, approximately 36 percent participated in training sessions, and about 20 percent received telephone consultation.

inspections conducted, the number and percentage of facilities that had penalties imposed fell substantially. The state imposed fewer civil fines, conditions on licenses, license revocations, and summary suspensions. Finding fewer problems during inspections also meant that each inspection required less time to complete and document, thereby allowing more efficient use of inspection resources.

Despite its broad support and favorable outcomes, the QIC program ended in July 2002. After 2 ½ years of operation, it lost its state funding and has since remained an unfunded program. According to state officials and consumer representatives, the program's end was primarily due to funding constraints. A severe state budget crisis in 2002 put significant pressure on DSHS to cut costs while maintaining its core functions of conducting inspection and complaint investigations. The department decided that it needed more inspectors for this work, and that licensing assistance through the QIC program had lower priority. However, the provider representative emphasized that insufficient trust between providers and the state also contributed to the program's end. While the evaluation results pointed to substantial success overall in building functioning relationships, the provider representative described several incidents of broken confidentiality between providers and consultants that tended to undermine the providers' willingness to participate in the program. A state official as well as consumer and provider representatives noted that the QIC program required collaboration and the sharing of sensitive information. Such collaboration depended on providers and consultants developing and sustaining trust among themselves, as well as between consultants and other state officials, such as inspectors and ombudsmen.

Washington's QIC program illustrates both the challenges and potential benefits of state efforts to provide licensing assistance to assisted living providers. A large number of providers chose to take advantage of the consultative services and training offered by the program. Moreover, the documented improvements in resident outcomes and in provider compliance with regulations demonstrate the impact that programs of this sort can have. However, the staff resources needed to provide this level of assistance make these programs highly vulnerable in times of budgetary constraint.

State Efforts to Strengthen Residents' Complaint Procedures

Some assisted living residents have difficulty pursuing complaints with their providers, particularly in cases involving an involuntary discharge. Georgia has established a spectrum of procedural remedies specifically for assisted living residents that appear to strengthen their bargaining position vis-a-vis providers. Massachusetts created a separate ombudsman staff dedicated to assisted living residents. As a result, these staff members have become expert in dealing with the particular problems of assisted living residents.

Residents Often Have Difficulty Raising Complaints about Their Facilities' Services and Policies

Concerns about problems in assisted living facilities reinforce the need to ensure that consumers have adequate mechanisms to raise complaints about the care they receive in these facilities.²⁸ For the most part, these mechanisms fall into two broad categories:

- Internal procedures, which specify how residents may lodge complaints with the facility's management and how management may respond.
- External procedures, which designate an entity outside of the facility to hear resident complaints and decide on an appropriate resolution. The outside entity may be a state agency or an independent third party. Such procedures are most commonly applied to major disputes, such as involuntary discharges.

A national study found that some states require assisted living facilities to establish internal complaint procedures, some offer residents a venue for external appeals, and some offer both.²⁹ In addition, it noted that some states take measures to ensure that assisted living residents are aware of these rights, for example by requiring that facilities prominently post appropriate telephone numbers and the list of resident rights in that state. However, the national study also found that in 2000 over half of the states had no requirements that assisted living facilities establish procedures for residents to voice complaints or appeal provider decisions that adversely affect them.

²⁸For information about significant care and safety problems in assisted living see [GAO/HEHS-99-27](#); *Policy Principles for Assisted Living* (April 2003); Assisted Living Workgroup, *Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations* (April 2003).

²⁹Stephanie Edelstein and Karen Gaddy, *Assisted Living: Summary of State Statutes* (Washington, D.C., AARP Public Policy Institute: 2000).

Regardless of their rights to file complaints either internally or externally, many residents may hesitate to do so for fear of retribution. According to the experts we interviewed and studies of ombudsmen programs, many assisted living residents do not want to risk alienating their providers. Even when state agencies permit the residents to file complaints anonymously, they may find it difficult to maintain their anonymity, especially in smaller facilities.

Among the avenues for residents to seek redress of their complaints is through the long-term care ombudsmen program in each state. The Older Americans Act directs ombudsmen to represent the interests of residents of long-term care facilities, including nursing homes and assisted living facilities.³⁰ The act authorizes the ombudsmen to serve as advocates to protect the health, safety, welfare, and rights of residents of long-term care facilities. One of the main responsibilities of ombudsmen is to investigate and resolve complaints.³¹ Ombudsmen involvement in assisted living varies considerably depending on state policies and the resources available to address the myriad complaints that they receive from all types of long-term care facilities. However, experts we interviewed noted that most ombudsmen focus the bulk of their limited resources on nursing homes. In fiscal year 2002, ombudsmen received four times as many complaints against nursing homes as assisted living facilities.³²

Ombudsmen can help overcome the factors that may inhibit assisted living residents from filing complaints. During scheduled visits to assisted living facilities, ombudsmen have the opportunity to educate residents on their right to file complaints and encourage them to do so. In addition, while the ombudsmen are on-site they can receive such complaints discretely.

³⁰42 U.S.C. § 3058g (2000) (originally enacted as § 712 of the Older Americans Act of 1965 by Pub. L. No. 102-375, § 702, 106 Stat. 1195,1275 (1992)).

³¹Ombudsmen may receive complaints from residents, family, friends, or facility staff. Ombudsmen may also initiate a complaint based on their own observations. Depending on state regulations and the nature of the complaint, ombudsmen may refer the complaint to another agency, such as the state licensing agency or adult protective services.

³²There were 208,762 nursing home complaints compared to 49,463 assisted living complaints in FY 2002, according to data from the U.S. Administration on Aging, representing over twice as many complaints per resident for nursing homes as for assisted living facilities. Among the top categories of complaints for assisted living were discharges, billing charges, staffing shortages, resident care and safety issues. U.S. Administration on Aging, National Ombudsman Reporting System Data FY 2002.

However, financial constraints may limit the frequency with which ombudsmen meet with assisted living residents.

Georgia Strengthens Procedural Remedies for Assisted Living Residents

In 1994, Georgia strengthened procedural remedies available to residents in assisted living facilities by enacting the Remedies for Residents of Personal Care Homes Act.³³ These remedies provide additional consumer protections beyond the investigation of complaints by its licensing agency, the Office of Regulatory Services (ORS) within the Department of Human Resources. The state gave assisted living residents specific procedural rights to have their complaints heard and redressed. The remedies include the right to an internal complaint procedure, an administrative hearing, and specified actions in court. According to consumer advocates, the 1994 law has enhanced the ability of assisted living residents to resolve disputes informally with assisted living providers.

At the time Georgia passed this legislation, assisted living facilities had recently come under heightened public scrutiny. Consumer advocates and the media had raised concerns about the lack of adequate oversight, as evidenced by facilities that maintained extremely poor sanitary conditions or that admitted residents who required far greater care than the facility could provide.³⁴ In response, the state legislature sought to provide assisted living residents with additional consumer protections by creating procedural remedies specifically for them. In its legislative findings, the state legislature recognized that residents often lacked the ability to assert their rights and stated that full consumer protection required that residents have a means of recourse when their rights were denied. According to the state official, the legislature modeled the act's procedural remedies after remedy options given to nursing home residents through both state and federal law.

³³1994 Ga. Laws 461, § 2 (Ga. Code Ann. §§ 31-8-130 et seq. (2003)). In Georgia, "assisted living facilities" are referred to as "personal care homes."

³⁴The absence of state regulatory authority over assisted living facilities exacerbated these problems. At that time, local public health districts had oversight responsibility for assisted living facilities, but according to the state official we interviewed, they lacked the resources and expertise to perform this function effectively. In 1994, ORS assumed responsibility for regulating assisted living facilities.

The remedies provided in the 1994 legislation include an internal complaint procedure and an administrative hearing.³⁵ Residents³⁶ may submit an oral or written complaint to a facility administrator, who must either resolve the complaint or respond in writing within 5 business days. If residents do not find the response satisfactory, they may submit an oral or written complaint to the state long-term care ombudsman. Residents also have the right to request an administrative hearing under the Georgia Administrative Procedure Act.³⁷ They are not required to use any other legal remedies before requesting such a hearing. The Office of State Administrative Hearings (OSAH) must conduct the hearing within 45 days of receiving the request, although state officials may refer the request to an ombudsman for informal resolution pending the hearing. If the resident alleges that the provider acted in retaliation for the resident exercising his or her rights, OSAH must conduct the hearing within 15 days of receiving the request. The facility cannot transfer a resident before he has exhausted all appeal rights unless he develops a serious medical condition or his behavior or condition threatens other residents.

The act also gives residents access to different types of court proceedings. A resident may file a lawsuit seeking compensation from an assisted living facility. The resident need not exhaust any of the other legal remedies before bringing such a suit. This remedy includes a provision designed to protect residents from retaliation by a provider. If the provider attempts to remove the resident involuntarily from the facility within 6 months after the resident exercises one of the available remedies, the court presumes retaliation in an action by the resident making that claim unless the provider presents “clear and convincing evidence” to the contrary. Residents may also file a lawsuit requesting that the court order a facility to refrain from violating the rights of a resident. Finally, residents may file a lawsuit for ‘mandamus’—a court order to ORS to comply with laws relating to an assisted living facility or its residents.

These procedural remedies appear to have their greatest effect in strengthening the position of residents during informal resolution of disputes. The legal aid representatives we interviewed noted that they

³⁵The legislation uses the term grievance.

³⁶A representative or legal surrogate of the resident may also pursue the remedies on behalf of the resident.

³⁷Ga. Code Ann. §§ 50-13-1 et seq. (2003).

resolve most issues between assisted living residents and providers informally. Advocates for residents said that these procedural remedies give the advocates added leverage as they negotiate with providers. However, advocates also stated that they rarely take the next step of actually filing for administrative hearings or court proceedings, in part because legal aid cases generally do not reach that step and also because they believe that the substantive rights of assisted living residents in Georgia are not strong. For example, a resident objecting to an involuntary discharge is unlikely to prevail in an administrative hearing because providers exercise broad discretion in deciding when they can no longer properly care for a resident. However, by requesting a hearing, residents can postpone the date by which they must move out, thereby gaining more time in which to find a suitable place to relocate. Moreover, according to one legal aid attorney, providers often prefer to resolve a dispute informally rather than take their chances with an administrative hearing, because providers typically have little experience with hearings and prefer to limit their costs for legal representation.

Strengthening Georgia's procedural remedies for assisted living residents required action by the state legislature, but once approved, the procedures have imposed minimal costs to the state. An agency to deal with a wide range of state administrative issues already existed, and with few hearings involving assisted living residents actually conducted, these cases represent a small portion of OSAH's operating expenses. Similarly, the state's long-standing advocates for assisted living residents—long-term care ombudsmen and legal aid lawyers—have served to inform both providers and residents about these legal remedies while carrying out their normal functions. In fact, providers and residents may remain unaware of their existence, until the advocates have reason to bring these remedies to their attention in the course of resolving disputes.

Massachusetts Established an Ombudsman Program for Assisted Living

In 1994, Massachusetts passed an assisted living statute³⁸ that established a statewide assisted living ombudsman program. The program is a key element of the statute, which created a certification system for assisted living separate from the state's nursing home regulatory and licensure system. According to the state official we interviewed, the primary purpose of this ombudsman program is to maintain the quality of life, health, safety, welfare, and rights of assisted living residents by

³⁸1994 Mass. Acts 354, § 3 (Mass. Gen. Laws Ann. ch. 19D, § 7 (2004)).

designating ombudsman staff specifically for assisted living. It provides a means for assisted living residents and family members to file and resolve complaints relating to the quality of services and to residents' quality of life. However, the program's exclusive reliance on state funding, under circumstances of state budgetary constraint, has resulted in limited staff resources available to perform these tasks.

Assisted living ombudsmen serve primarily as mediators and advocates. As mediators, they receive, investigate, and attempt to resolve problems or conflicts that occur between a provider and residents. They act as advocates for residents by referring their cases to the assisted living certification office or elder protective services, when warranted. In addition, the ombudsmen respond to inquiries by consumers considering assisted living as a long-term care option. They also respond to providers requesting advice. To accomplish these tasks, the ombudsmen make site visits to assisted living facilities, typically in the context of a serious complaint allegation and sometimes together with certification staff.

The organizational placement of the ombudsman program within the state's Executive Office of Elder Affairs (EOEA) is designed to balance program autonomy and coordination with related programs. EOEA oversees both the assisted living ombudsman and certification programs. According to the state official, staff members from both programs coordinate activities, communicate often, and refer cases to each other. This working relationship has helped give the ombudsman more leverage when dealing with providers. However, representatives for both the state and assisted living providers agree that the ombudsman program should remain separate organizationally from the certification program because they perform different functions. Previously, when the staff of the two programs had reported to the same individual in EOEA, providers became confused about the programs' respective roles during a visit. A subsequent restructuring of EOEA placed the certification and ombudsmen in separate divisions.

Shared EOEA administration also links the assisted living ombudsmen to other programs serving elderly clients, such as elderly protective services and the long-term care ombudsmen program. The state has emphasized coordination with elderly protective services to ensure that assisted living residents found in abusive situations quickly receive the help they need.³⁹

³⁹ See U.S. General Accounting Office, *Nursing Homes: More Can Be Done to Protect Residents from Abuse*, GAO-02-312 (Washington, D.C.: Mar. 1, 2002).

In addition, by placing assisted living ombudsmen in the same office of EOEAs as long-term care ombudsmen, Massachusetts has attempted to maintain a degree of communication and coordination across the different long-term care settings. As described by the provider representative we interviewed, this arrangement allows for “cross-fertilization” between the different programs. Although the programs differ substantially in their approach to ensuring quality care, assisted living ombudsmen can nevertheless draw upon the decades-long experience residing in the long-term care program.⁴⁰

Massachusetts’ assisted living ombudsman program regulations⁴¹ called for a structure similar to that of the existing long-term care ombudsman program. According to the state official, the long-term care ombudsman program has a full-time training position and several regional coordinators responsible for recruiting, training, and overseeing volunteers who make site visits to nursing homes on a regular basis throughout the state. However, according to the state official, the assisted living ombudsman program never received sufficient funding to develop this type of structure. Although the regulations authorized a similar network of volunteers, the program staff has consisted of no more than three professionals, later reduced to two, who handle complaints and inquiries for 172 assisted living facilities. That left no one available to recruit, train, and supervise volunteers, and consequently, visits to facilities only occurred in response to complaints and not on a routine basis.

The Massachusetts legislature funded the assisted living ombudsman program by creating an assisted living administrative fund,⁴² which received the fees paid biennially by facilities as part of the certification process. The ombudsman shared these funds with the assisted living certification staff. However, in response to statewide budgetary pressures, the legislature eliminated this fund in fiscal year 2003 and redirected the

⁴⁰The state official we interviewed described how the state’s vision of assisted living follows the “social model,” while the Department of Public Health applies the “medical model” to nursing homes and related institutions. The social model seeks to create a homelike environment that emphasizes independence over the provision of health care services or personal care assistance. The medical model focuses more on clinical issues, such as proper medication and nursing services. The state’s long-term care ombudsman program correspondingly follows the medical model approach while the assisted living ombudsman program adheres to the social model.

⁴¹Mass. Regs. Code tit. 651, §§ 13.00 et seq.

⁴²1995 Mass. Acts 38, § 45 (Mass. Gen. Laws Ann. ch. 29, § 2BB (1995)).

certification fees to the state's general revenues.⁴³ Meanwhile, the long-term care ombudsman program continued to operate largely with federal funds, authorized under the Older Americans Act.

The state and provider representatives we spoke with agreed that having a separate assisted living ombudsman program led its staff to become increasingly knowledgeable about assisted living and the particular problems that arise within it. Both providers and residents benefit from the fact that assisted living ombudsmen do not have to balance the needs of residents from different types of long-term care facilities. However, the decision to fund the program solely through the state made it especially vulnerable to budgetary cutbacks when Massachusetts faced constrained fiscal circumstances. Although the federally supported state long-term care ombudsman programs also contend with scarce resources nationwide, the Massachusetts assisted living ombudsman program highlights the difficulty of sustaining this type of program with state funds alone.

Concluding Observations

Florida, Texas, Washington, Georgia, and Massachusetts have each found ways to enhance the experience of assisted living residents in their states. They have done so by developing information resources, expanding complaint mechanisms, or allocating state resources to assisted living programs. However, those initiatives that required increases in state staff or funds fared less well during periods of fiscal constraint. The demise of the Washington QIC program, despite its well-documented favorable outcomes, and cutbacks in the popular Massachusetts assisted living ombudsman program, reflect the vulnerability of any discretionary state program to budget reductions. Florida's Web site, Texas' disclosure form, and Georgia's procedural remedies, by contrast, have benefited from the important advantage that none of these programs required substantial resources to initiate and maintain. These examples from five states can perhaps aid other states in developing their own approaches to helping senior citizens take full advantage of assisted living alternatives to nursing home care.

⁴³2003 Mass. Acts 26, §140 (effective June 30, 2003) (Mass. Gen. Laws Ann. ch. 29, § 2BB (2004)).

Comments from the States

We sent sections from an earlier draft of this report to state officials in Florida, Texas, Washington, Georgia, and Massachusetts and asked them to check that the section accurately described the development and implementation of their state's program. Officials from all five states responded and provided technical comments that we incorporated where appropriate.

As agreed with your offices, unless you publicly announce the contents of this report earlier, we plan no further distribution of it until 30 days from its date. At that time, we will send copies of this report to interested parties. In addition, this report will be available at no charge on GAO's Web site at <http://www.gao.gov>. We will also make copies available to others upon request.

If you or your staff have any questions about this report, please call me at (312) 220-7600. An additional contact and other staff members who prepared this report are listed in appendix IV.



Leslie G. Aronovitz
Director, Health Care—Program
Administration and Integrity Issues

Appendix I: Key Sources Consulted

National Organizations and Academic Experts

Alzheimer's Association
American Association of Homes and Services for the Aging
American Bar Association Commission on Law and Aging
American Seniors Housing Association
Assisted Living Federation of America
Association of Health Facility Survey Agencies
Consumer Consortium on Assisted Living
National Association for Regulatory Administration
National Association of State Long-Term Care Ombudsman Programs
National Association of State Units on Aging
National Center for Assisted Living
National Citizens' Coalition for Nursing Home Reform
NCB Development Corporation, The Coming Home Program

Catherine Hawes, Texas A&M University
Robert Mollica, National Academy for State Health Policy
Janet O'Keeffe, Research Triangle Institute

Major Studies on Assisted Living

Catherine Hawes, et al., *A National Study of Assisted Living for the Frail Elderly: Results of A National Survey of Facilities* (Beachwood, Ohio: December 1999).

Maureen Mickus, "Complexities and Challenges in the Long Term Care Policy Frontier: Michigan's Assisted Living Facilities" (Michigan State University Applied Public Policy Research Program: September 2002).

Robert Mollica and Robert Jenkins, *State Assisted Living Practices and Options: A Guide for State Policy Makers* (National Academy for State Health Policy and NCB Development Corporation: September 2001).

Janet O'Keeffe, et al., *Using Medicaid to Cover Services for Elderly Persons in Residential Care Settings: State Policy Maker and Stakeholder Views in Six States*, Research Triangle Institute, prepared at the request of the U.S. Department of Health and Human Services (December 2003).

Charles D. Phillips, et al., *Residents Leaving Assisted Living: Descriptive and Analytic Results from a National Survey*, prepared at the request of the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, June 2000.

Brenda Spillman et al., *Trends in Residential Long-Term Care: Use of Nursing Homes and Assisted Living and Characteristics of Facilities and Residents*, Washington, D.C.: Urban Institute, prepared at the request of the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, November 2002.

U.S. General Accounting Office, *Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States*, [GAO/HEHS-99-27](#) (Washington, D.C.: Apr. 26, 1999)

U.S. General Accounting Office, *Long-Term Care: Consumer Protection and Quality-of-Care Issues in Assisted Living*, [GAO/HEHS-97-93](#) (Washington, D.C.: May 15, 1997).

Guides on State Assisted Living Regulations

American Seniors Housing Association, *Seniors Housing: State Regulatory Handbook*, March 2003.

Lyn Bentley, *Assisted Living State Regulatory Review 2004*, National Center for Assisted Living (March 2004).

Stephanie Edelstein, et al., *Assisted Living: Summary of State Statutes* (in 3 volumes) AARP, 2000.

Robert Mollica, *State Assisted Living Policy: 2002* (Portland, Maine: National Academy for State Health Policy, November 2002).

State-level Entities

We interviewed officials or individuals associated with the following entities:

Florida Department of Elder Affairs
Florida Assisted Living Affiliation
Senior Resource Alliance (Florida)
Texas Department of Human Services
Texas Assisted Living Association

Texas Assisted Living Advisory Committee
Washington Department of Social and Health Services
Washington Health Care Association
Washington Long-term Care Ombudsman Program
Georgia Long-Term Care Ombudsman Program
Georgia Legal Aid Program
Senior Citizens Law Project (Georgia)
Assisted Living Association of Georgia
Massachusetts Executive Office of Elder Affairs
Massachusetts Assisted Living Facilities Association

State-level Studies

Alice Mahar Dupler, Neva L Crogan, and Robert Short, "Pathways to quality improvement for boarding homes: A Washington state model," *Journal of Nursing Care Quality*; Jul 2001; 15(4), 1-7.

Alice Mahar Dupler, "Quality Improvement Consultation Program in Assisted Living Facilities, A Washington State Pilot Program: Phase II," unpublished, no date.

Appendix II: Florida Affordable Assisted Living “Find-a-Facility” Consumer Search

To begin your search, please enter a zip code or select a county:

Zip Code OR County

Select payment option(s):

- Private Pay
- Government Subsidies Accepted

Select monthly price range:

- under \$800
- \$800-\$1200
- \$1201-\$1600
- \$1601-\$2000
- Over \$2000

Select residential unit preference(s):

- Single Occupancy Unit
- Double/Multiple Occupancy Unit
- Individual Apartment with Kitchen
- Fully Furnished
- Private Bath
- Pets Allowed
- Dementia (Secured) Units

Select all services you are seeking:

- Adult Day Care Service
- Alzheimer’s Disease / Dementia Care
- Assistance with Medications
- Assistance with the activities of daily living (ADLs)
- Assistance with Transferring
- Escort Service for Medical Appointments
- Incontinence Care
- Individual Personal Care Attendant
- Kosher Meals
- Licensed Nurse on Duty
- Medication Administration by Licensed Nurses
- Respite (Short term) Care
- Special Diets
- Special Language Preference

Select all special accommodations and services you are seeking:

- ALE Medicaid Waiver Provider
- Emergency Placement
- Extended Congregate Care Services
- Full Laundry Service
- Independent Living Units
- Limited Nursing Services
- Skilled Nursing Unit
- Transportation Service
- Wellness Center

Select special residency requirements:

- Catheter
- Developmentally Disabled
- Diabetic
- Hospice (Must meet admission criteria)
- Stage 1 or 2 Decubitus Ulcer (Pressure Sore)
- Visual/Hearing Impairment
- Wheelchair-bound

Source: <http://www.floridaaffordableassistedliving.org>

Appendix III: Texas Assisted Living Disclosure Statement

Texas Department
of Human Services

ASSISTED LIVING DISCLOSURE STATEMENT

Form 3647
April 2000

The purpose of this Disclosure Statement is to empower consumers by describing a facility's policies and services in a uniform manner. This format gives prospective residents and their families consistent categories of information from which they can compare facilities and services. By requiring the Disclosure Statement, the department is not mandating that all services listed should be provided, but provides a format to describe the services that are provided.

The Disclosure Statement is not intended to take the place of visiting the facility, talking with residents, or meeting one-on-one with facility staff. Rather, it serves as additional information for making an informed decision about the care provided in each facility.

INSTRUCTIONS TO THE FACILITY

1. Complete this Disclosure Statement according to the care and services that your facility provides. You may not amend the statement, but you may attach an addendum to expand on your answers.
2. Provide copies of and explain this Disclosure Statement to anyone who requests information about your facility.

Facility Name	License No.	Average No. Residents	Telephone No.
Address (Street, City, State, ZIP)			
Manager			Date Disclosure Statement Completed
Completed By:		Title	

The Assisted Living Licensure Standards are available for review at all assisted living facilities.
A copy of the most recent survey report may be obtained from facility management.

To register a complaint about an assisted living facility, contact:
Texas Department of Human Services at 1-800-458-9858.

I. PRE-ADMISSION PROCESS

A. Indicate services which are not offered by your facility:

- Assistance in transferring to/from wheelchair
 Medication injections
 Oxygen administration
 Behavior management for verbal aggression
 Bladder incontinence care
 Feeding residents
 Special diets
 Behavior management for physical aggression
 Bowel incontinence care
 Intravenous (IV) therapy
 Other: _____

B. What is involved in the pre-admission process?

- Facility tour
 Family interview
 Medical records assessment
 Application
 Home assessment
 Other: _____

C. What services and/or amenities are included in the base rate?

- Meals (_____ per day.)
 Temporary use of wheelchair/walker
 Select menus
 Housekeeping (_____ days per week.)
 Barber/beauty shop
 Licensed nurse (_____ hours per day.)
 Activities program (_____ days per week.)
 Special diet
 Injections
 Incontinence care
 Personal laundry
 Transportation (specify): _____
 Other: _____

Appendix III: Texas Assisted Living Disclosure Statement

Form 3647
Page 2

D. What additional services can be purchased?

- | | | |
|---|--|--|
| <input type="checkbox"/> Beauty/barber services | <input type="checkbox"/> Injections | <input type="checkbox"/> Minor nursing services provided by facility staff |
| <input type="checkbox"/> Incontinence care | <input type="checkbox"/> Companion | <input type="checkbox"/> Home health services |
| <input type="checkbox"/> Incontinence products | <input type="checkbox"/> Transportation to doctor visits | |
| <input type="checkbox"/> Other: _____ | | |

E. Do you charge more for different levels of care? Yes No

II. ADMISSION PROCESS

A. Does the facility have a written contract for services? Yes No

B. Is there a deposit in addition to rent? Yes No

If yes, is it refundable? Yes No

If yes, when? _____

C. Do you have a refund policy if the resident does not remain for the entire prepaid period? Yes No

If yes, explain: _____

D. What is the admission process for new residents?

- | | | | |
|--|--|---|--|
| <input type="checkbox"/> Doctors' orders | <input type="checkbox"/> Residency agreement | <input type="checkbox"/> History and physical | <input type="checkbox"/> Deposit/payment |
| <input type="checkbox"/> Other: _____ | | | |

E. Does the facility have provisions for special resident communication needs?

- | | |
|--|---|
| <input type="checkbox"/> Staff who can sign for the deaf | <input type="checkbox"/> Services for persons who are blind |
| <input type="checkbox"/> Other (explain): _____ | |

F. Is there a trial period for new residents? Yes No

If yes, how long? _____

III. DISCHARGE/TRANSFER

A. What could cause temporary transfer to specialized care?

- | | |
|---|---|
| <input type="checkbox"/> Medical condition requiring 24 hour nursing care | <input type="checkbox"/> Unacceptable physical or verbal behavior |
| <input type="checkbox"/> Drug stabilization | <input type="checkbox"/> Resident requires services the facility does not provide |
| <input type="checkbox"/> Other: _____ | |

B. The need for the following services could cause permanent discharge:

- | | | |
|--|--|--|
| <input type="checkbox"/> 24 hour nursing care | <input type="checkbox"/> Sitters | <input type="checkbox"/> Medication injections |
| <input type="checkbox"/> Assistance in transferring to and from wheelchair | <input type="checkbox"/> Bowel incontinence care | <input type="checkbox"/> Feeding by staff |
| <input type="checkbox"/> Behavior management for verbal aggression | <input type="checkbox"/> Bladder incontinence care | <input type="checkbox"/> Oxygen administration |
| <input type="checkbox"/> Behavior management for physical aggression | <input type="checkbox"/> Intravenous (IV) therapy | <input type="checkbox"/> Special diets |
| <input type="checkbox"/> Other: _____ | | |

C. Who would make this discharge decision?

- | | |
|---|---------------------------------------|
| <input type="checkbox"/> Facility Manager | <input type="checkbox"/> Other: _____ |
|---|---------------------------------------|

D. Do families have input into these discharge decisions? Yes No

E. Is there an avenue to appeal these decisions? Yes No

F. Do you assist families in making discharge plans? Yes No

IV. PLANNING AND IMPLEMENTATION OF CARE (check all that apply)

A. Who is involved in the service plan process?

- Resident Family members Activity director Attendants Manager
 Licensed nurses Social worker Dietary Physician
 Other: _____

B. Does the service plan address the following?

- Medical needs Nursing needs Activities of daily living Psychosocial needs Nutritional status Dental status
 Other: _____

C. How often is the service plan assessed?

- Monthly Quarterly Annually As needed
 Other: _____

D. How many hours of structured activities are scheduled per day?

- 1-2 Hours 2-4 Hours 4-6 Hours 6-8 Hours 8+ Hours

E. What types of programs are scheduled?

- Music program Arts program Crafts Exercise Cooking
 Other: _____

F. Who assists with or administers medications?

- RN LVN Medication aide Attendant
 Other: _____

V. CHANGE IN CONDITION ISSUES

What special provisions do you allow for aging in place?

- Sitters Additional services agreements Hospice Home health—If so, is it affiliated with your facility? Yes No
 Other: _____

VI. STAFF TRAINING

A. What training do new employees receive?

- Orientation: _____ hours Review of resident service plan On the job training with another employee: _____ hours
 Other: _____

B. Is staff trained in CPR? Yes No

If no, please explain why you do not require CPR training: _____

C. How much on-going training is provided and how often? (Example: 30 minutes monthly): _____

D. Who gives the training and what are their qualifications? _____

E. What type of training do volunteers receive?

- Orientation: _____ hours On the job training
 Other: _____

F. In what type of endeavors are volunteers engaged?

- Activities
 Meals
 Religious services
 Entertainment
 Visitation
 Other: _____

G. List volunteer groups involved with the facility:

VII. PHYSICAL ENVIRONMENT

A. What safety features are provided in your building?

- Emergency call system
 Fire alarm system
 Built according to NFPA Life Safety Code, Chapter 12, Health Care
 Sprinkler system
 Wander Guard or similar system
 Built according to NFPA Life Safety Code, Chapter 21, Board and Care
 Other: _____

B. Does the facility's environment include the following?

- Plants
 Pets
 Vegetable/flower gardens for use by residents
 Other: _____

C. Are the residents allowed to have:

- Plants
 Pets—If so, is a deposit required? Yes No
 How much? \$ _____

VIII. STAFFING PATTERNS

A. What are the qualifications of the manager?

B. Please list the facility's normal 24-hour staffing pattern on:

1. the attached chart; or
 2. a separate attachment which explains your facility's unique staffing policies and patterns.

IX. RESIDENTS' RIGHTS

A. Do you have a Resident's Council? Yes No

How often does it meet? _____

B. Do you have a Family Council? Yes No

How often does it meet? _____

C. Does the facility have a formal procedure for responding to resident grievances and suggestions for improvement? ... Yes No

Is there a Grievance Committee? Yes No

Is there a Suggestion Box? Yes No

D. How can the company that owns the facility be contacted?

SHIFT TIMES AND STAFFING PATTERNS AT THE FACILITY

Full-Time Personnel

SHIFTS (Enter the hours of each of your facility's shifts.)	NUMBER OF STAFF PER SHIFT						
	R.N.s	L.V.N.s	Attendants	Medication Aides	Activity Workers	Universal Workers	Other Workers

Part-Time Personnel

SHIFTS (Enter the hours of each of your facility's shifts.)	NUMBER OF STAFF PER SHIFT						
	R.N.s	L.V.N.s	Attendants	Medication Aides	Activity Workers	Universal Workers	Other Workers

Appendix IV: GAO Contact and Staff Acknowledgments

GAO Contact

Rosamond Katz, (202) 512-7148

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