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Growth and Development of the Assisted Living Industry

The U.S. General Accounting Office issued a report on quality of care and consumer protection issues in assisted living residences. The following is an excerpt of William F. Lasky's testimony, on behalf of the Assisted Living Federation of America, at the Senate Special Committee on Aging hearing that addressed this report.

By William F. Lasky

The Assisted Living Federation of America (hereinafter ALFA) is the only national trade association devoted exclusively to the assisted living industry and the population it serves. ALFA's 6,000-plus members include for-profit and non-profit, large and small assisted living providers. ALFA members operate freestanding assisted living, continuing care retirement communities, and other entities that may have an assisted living wing,

such as hospital systems, nursing homes, and independent living residences. ALFA has 31 state affiliates covering 34 states to work with regulators and legislators on the state level. ALFA's primary mission is to promote the interest of the assisted living industry as well as to enhance the quality of life for the residents and family members it serves. In keeping with that goal, ALFA has worked to educate providers and consumers to ensure that customer satisfaction, quality of life, and quality of care are paramount in assisted living.

The findings of the U.S. General Accounting Office (hereinafter GAO) report, which is the subject of this hearing, address the issues of quality of care and consumer protection in the assisted living industry. The report's findings are based on data gathered from survey responses and interviews with assisted living providers, residents and family members, and state regulators in California, Oregon, Ohio, and Florida. Since we were permitted only a brief review of the GAO's findings prior to today's hearing, we respectfully request the opportunity to add to our written testimony after we have had a chance to more completely study and evaluate the report.

As requested by the committee, my remarks today address the concept of aging in place, how this philosophy may impact the concerns of the committee, and why the assisted living industry supports this concept.

Definition of Assisted Living

Assisted living, as defined by ALFA, is a combination of housing, health care, and supportive services designed to respond to the individual needs of those who require help with activities of daily living but not necessarily the round-the-clock skilled medical care provided in other long-term care set-

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tings. Trained staff members are available 24 hours a day to allow residents to age in place and receive the support and assistance they require to meet their changing health care and personal needs. The typical assisted living resident is a single or widowed woman in her 80s who on average needs help with three activities of daily living, such as bathing, dressing, or taking medications.

Assisted living residences typically provide a less expensive, more residential approach to delivering some of the same types of services found in a skilled nursing facility. They adjust on-site services to a resident's acuity level as the resident's needs change, or access services from home health care, hospice, and other community-based professionals. The needs of many individuals with either physical or cognitive limitations can be met within an assisted living environment. Providers also have specialties such as serving elders with Alzheimer's disease or younger residents with disabilities.

The assisted living industry, with the assistance of ALFA, has embraced a philosophy to guide operators and ensure that quality care is provided at each residence. The ALFA 10-point philosophy includes:

- Offering cost-effective quality care personalized for the individual's needs
- Fostering independence for each resident
- Treating residents with respect and dignity
- Promoting the individuality of each resident
- Allowing each resident a choice of care and lifestyle
- Protecting each resident's right to privacy
- Nurturing the spirit of each resident
- Involving family and friends in the planning and implementation of care
- Providing a safe, residential environment
- Making the residence a valuable community asset.

To further our commitment to the 10-point philosophy, ALFA has created an ethics/mission statement that clearly communicates our members' commitment to the well-being of our residents and family members.

Industry History

We are a young, dynamic industry that continues to evolve. In the 1980s, a new generation of caregiving

settings dedicated to a residential, homelike environment came into being, in response to consumers' wishes for alternatives to traditional long-term care settings. These early customers were willing to forgo existing entitlement programs in institutional settings by paying out of their personal funds so that they or their loved one could enjoy a more residential, homelike environment. In other words, they were willing to share the responsibility associated with this new, more flexible model in order to preserve their independence for as long as possible. As a result, consumer desire to find a noninstitutional option has shaped the design and service delivery in assisted living residences in every state.

Since then, the industry has evolved from a cottage industry to an estimated \$13 billion industry that is working to meet the care needs of consumers who want greater choice and more alternatives to long-term care. Driven by market forces and customer demand, the assisted living movement has become the option of choice for many seniors nationwide. Increased competition has further empowered customers to choose from a variety of providers and find the setting that best meets their own personal needs or preferences.

The consumer who chooses assisted living has evolved along with the industry. Over the last 10 years, nursing homes have begun caring for patients with higher acuity levels who at one time would have been in a hospital setting. Likewise, many of yesterday's nursing home residents requiring intermediate care have become today's assisted living residents. This so-called push-down phenomenon has further fueled the growth of the assisted living industry. Assisted living providers have been evolving their building designs, programming, and service delivery to better meet the needs of increasingly frail residents.

A great variety of assisted living options exist today because of the wide range of consumer preferences, as well as state-by-state variations in licensing and regulations. Assisted living is regulated at the state level in each of the 50 states. The states vary widely as to the model they use for regulating assisted living, and the term "assisted living" is not always used to describe the licensure category. This can cause confusion and has led to the misconception that in many states the assisted living industry is not regulated. In fact, assisted living providers are regulated under a wide variety of

categories ranging from Homes for Aged in Michigan, to Residential Care Facilities for the Elderly in California, to Assisted Living Residences in Massachusetts.

Throughout the country, assisted living providers and ALFA state affiliates are partnering with consumer advocates, state regulators, and legislators to study, license, and incorporate assisted living into state long-term care systems. It is exciting to see each state government determine its own approach to quality oversight, allowing for much creativity and ingenuity. The states are approaching assisted living in a variety of ways ranging from developing new assisted living licensure, to covering assisted living services under existing board and care regulations, to studying and even piloting new regulatory approaches. Assisted living providers continue to work in partnership with consumers and state regulators to insist that independence, dignity, choice, and privacy are paramount in the regulatory oversight of the industry.

Aging in Place: A Definition

This brings us to the concept of “aging in place.” Just as with home and community-based delivery services, the ultimate goal of assisted living providers is to satisfy consumers’ desire to “age in place” as long as possible in a safe, residential environment. Assisted living residences have continued to evolve as the acuity and complexity of the average resident’s condition has changed. This has created the need to define and implement aging in place philosophies. We, as an industry, define aging in place as each resident’s choice to remain in his or her living environment (otherwise known as home) regardless of the physical or mental changes that may occur as he or she ages. The essence of aging in place is that a change of condition should not automatically mean a change of address. In assisted living residences, aging in place is facilitated by adding services and staff as needed to meet each resident’s changing needs.

Health Care Is Portable

In the past, and even now, generations of older adults have remained in their homes until the end of their lives supported and aided by family, friends, and neighbors. With advances in health care technology and community-based service options, such as home health care and hospice, many frail or ailing older Americans are able to

remain at home for the rest of their lives rather than receive care in an institutional setting such as a hospital or nursing home. This “portability” of health care services, coupled with the philosophy of aging in place, has led to assisted living residences becoming a place where a resident can spend the last years, months, or weeks of his or her life surrounded by family members, friends, caring staff members, and community health care professionals. As a result, residents and their families around the country have come to regard their community of neighbors and care providers in assisted living residences as their home, and long to remain at that home for the rest of their lives.

Customer Choice

Under the aging in place philosophy, residents and family members can make choices and are involved in the process of organizing their care. The choices consumers sometimes make can be risky for a provider. We as providers engage in a balancing act between what individual consumers want and what is safest for them. If a resident was prone to falling and that person was restrained, it would clearly prevent a fall. But it also would greatly diminish the resident’s quality of life and level of control. Our residents and their family members recognize and embrace our willingness to share the risks inherent in living in a residential environment. Our responsibility as providers is to clearly communicate which services will be provided by the residence staff, and which services the resident may need or desire to contract from the community.

A Positive Environment for Residents with Alzheimer’s Disease

Assisted living residences have come to be recognized as appropriate and desirable environments for individuals with Alzheimer’s disease and other forms of cognitive impairment to live and age in place. This notion is supported by the National Alzheimer’s Association and addressed in their publication *Residential Settings*, which offers guidelines and recommendations for providing care in assisted living residences. People affected by Alzheimer’s disease typically do not have a great need for medical treatment and intervention. Rather, many are in good physical health but need a secure, supportive environment with 24-hour assistance and supervision—a high-touch/low-tech setting in which to live and flourish. At one time,

the diagnosis of Alzheimer's disease translated into a life destined to end in a nursing home setting. Today, residents with Alzheimer's disease are able to live in supportive residential environments that focus on helping them and their families cope with the signs and symptoms of their progressive cognitive decline. Their ability to remain in a familiar, caring environment is vital to improving their daily lives and ability to function.

In response to customer demand for more homelike yet supportive settings for individuals with dementia, assisted living operators have developed many innovations for this special resident population. These include "memory" boxes outside residents' units, special way-finding systems throughout the residence, and walking paths through meaningful "life skills" rooms—such as an office, a tool shed, a woodworking area, and user-friendly kitchens—that allow residents to participate in everyday experiences that were once important and enjoyable to them.

Assessing and Monitoring Residents' Changing Needs

Designing and implementing a successful "aging in place" approach requires a partnership involving the resident, family members, residence staff, and health care professionals. At assisted living residences throughout the country, residents receive a baseline assessment when they arrive. This assessment, often completed by a registered nurse or other health care professional, establishes a diary of care needs and psychosocial issues. From this overview, a specific service plan is developed to guide the staff members who will interact with the resident and provide care. The service plan is a working tool that is continuously updated to reflect the changes that may occur as residents age or their preferences evolve. It should include the following resident information: health care needs, medications, physical abilities and limitations, ability to communicate, nutritional status/special dietary needs, cognitive status, psychological needs, need for assistance with activities of daily living, religious preferences, daily routine, and special interests. The individualized plan allows a staff to implement appropriate care programs and to revise the plans to meet each resident's changing needs. Typically, service plans are reevaluated at specific time intervals during the year or when an acute event occurs such as a stroke.

Assisted living caregivers are responsible for monitoring, observing, and communicating the residents' needs. By listening and observing, staff members can share their daily assessments with a resident's doctors, family, pharmacist, or other health care professionals involved in the resident's care. Most importantly, the resident and family members are empowered to become an active part of any problem-solving that may be required. Together, the resident, family, and the staff determine what services should be provided by the staff to meet the resident's changing needs. In some instances, a decision may be made that the resident's needs can be better met by bringing in community resources, such as hospice, to allow the individual to age in place. When a hospitalization is required, staff frequently coordinates with the family and the resident to provide or bring in the appropriate resources to facilitate the transition once the individual returns to the assisted living residence. Physical therapy, occupational therapy, or other services can be provided to help the resident regain functional abilities. Adapting staffing patterns, accessing home health services, and creating a specialized care program are decisions made as a team. This caring partnership allows residents to continue to navigate their own destiny as much as possible.

Barriers to Aging in Place

In their own home, individuals can age in place by contracting for any health care services they need. However, in some states, assisted living residents are prevented from obtaining services, on-site or from a contractor, even though the residence is also their home and legal domicile. Other states have recognized the value of allowing residents to remain in an assisted residence and have embraced the concept of aging in place. These states allow the assisted living residence to provide services to meet changes in the needs of an aging resident such as assistance with activities of daily living (i.e., bathing, dressing, ambulating), special diets, medications, incontinence care, and nursing care. Some states may preclude the assisted living residence from providing some of these services but allow the resident to receive support from outside providers such as home health care, therapy, or even hospice.

In states that do not allow aging in place, residents typically must be discharged to a higher level care setting when they no longer meet the state's

retention criteria. Depending on the state, residents might be discharged when they become incontinent, require assistance with transferring or walking, require assistance with more than the allotted number of activities of daily living, or need more than the allotted number of hours of nursing care in a week. There are even a few states that believe residents with Alzheimer's disease, regardless of their physical capabilities, must be placed in a nursing home and should not have the option of living in an assisted living residence.

Since health care is portable, many consumers believe that they should be entitled to receive the same level of health care within an assisted living residence as they would in a private home. The assisted living industry agrees with this perspective. State regulators should not require that residents be moved from their own home to a nursing home when their needs change. Yet that is the case if their home happens to be a supportive community environment like assisted living. Consumers are beginning to recognize that they have the right to choose where they live, irrespective of their age or physical condition. The Fair Housing Amendment Act of 1988 and the Americans with Disabilities Act of 1991 give civil rights backing to the demand that supportive services be provided to persons with disabilities of any age in living arrangements they may choose.

As a resident becomes more frail, the need for more staffing and services increases. Likewise, there is an associated increase in cost. For residents who have sufficient financial resources, this is generally not a problem. But for many older adults with more modest means, other types of long-term support are needed. Ten of the 12 largest long-term care insurance carriers now cover assisted living. In addition, at least 32 states provide for reimbursement for assisted living services through a variety of funding programs, such as Medicaid waiver programs. In the absence of these options, residents may be forced to move to the more costly and more medically intensive environment of a skilled nursing facility in order to access Medicaid funding, even if they do not require this higher level of care.

ALFA advocates are partnering with states to develop a variety of affordable options for reimbursement to maximize consumer choice. We are considering a variety of options including consumer care accounts, a voucher program, a Medicare partnership plan, and an individual long

term care block grant. We believe that any such system should allow portable funding for the consumer.

Consumer Protection

There is an erroneous perception that there is a lack of mechanisms to address quality issues and consumer protection. Assisted living providers are surveyed, or inspected, in almost every state prior to opening a residence and annually thereafter. Most states also have a mechanism where surveyors will visit the residence if a complaint is lodged with the state agency. The survey process itself varies from state to state ranging from a day visit with a surveyor to a three- to four-day inspection with three to four surveyors. Typically, the surveyor produces a written report of the inspection that is available to the general public, residents, families, and potential consumers. The surveyors can cite deficiencies, require plans to correct cited deficiencies, and take enforcement action.

In addition to local state health or social service departments that are responsible for licensure oversight, many states have other mechanisms in place to monitor quality and detect problems. For example, numerous states enlist ombudsmen to monitor quality, investigate and resolve complaints, assist in conflicts between providers and residents, and report unsolved problems to the appropriate authorities. Some states have Vulnerable Adult Acts mandating that doctors, clergy, professionals, or others report suspected problems. Assisted living providers are currently subject to all of these mechanisms developed to monitor quality when caring for the elderly. There also are fire and safety codes and building code regulations that govern the industry.

Ensuring Quality of Care

Listening and responding to customer preferences is critical to ensure quality in assisted living residences. By measuring and monitoring resident and family satisfaction, assisted living providers can take appropriate steps to provide responsive quality care. ALFA is in the process of analyzing interim findings on its National Satisfaction Survey, which will be released shortly and provided to members of the committee.

The traditional regulatory approach to long-term care has focused on minimum standards. As evidenced in the nursing home industry, this has

resulted in a highly prescriptive, high-cost, and institutional delivery of long-term care. These very factors have driven the consumer demand for assisted living. The desire of ALFA and its industry members is that quality measures should be consumer-centered, performance-oriented, and responsive to quality of life issues. The approach to quality must also enhance consumer choice and protect quality of life for vulnerable consumers whose choices may be limited due to cognitive capacity or lack of financial resources. Outcome-based regulations are all about setting goals as opposed to making broad-based minimum requirements that may lead to institutional-type solutions.

ALFA and its members have been working through a variety of channels such as the Assisted Living Quality Coalition (hereinafter ALQC) to continually improve existing regulations or develop new regulations that focus on quality outcomes. Quality indicators should measure actual outcomes, such as how well a resident is doing medically, functionally, in terms of his or her satisfaction, and quality of life. When the consumer rather than the government is the payer, the consumer must be allowed to be part of the quality oversight process.

The Quality Coalition, consisting of six organizations representing both providers and consumers, has been working since 1996 to develop a collaborative quality initiative for assisted living. In addition to ALFA, members of the coalition include the Alzheimer's Association, the American Association of Homes and Services for the Aging (AAHSA), the American Association of Retired Persons (AARP), the American Health Care Association (AHCA), and the American Seniors Housing Association (ASHA).

The Quality Coalition has based its ongoing work on two goals:

- Promote the highest possible quality of life for older persons and consumers with disabilities by advocating for the assisted living philosophy of independence, privacy, dignity, and autonomy
- Lay a foundation for the continued growth of assisted living by fostering a quality improvement system that demands and rewards quality

To date, the ALQC has produced an overall framework for implementing the initiative, includ-

ing guidelines to states on establishing minimum standards, which are the result of the coalition's research, brainstorming, numerous input forums, and, most importantly, compromise. These guidelines are meant to provide guidance to state legislators and agencies for finessing their own regulations and quality initiatives and are not intended as strict "standards of care." The guidelines are meant to evolve over time and should be viewed within the parameters of existing progressive and innovative state programs. ALFA is pleased that the coalition was able to bring about consensus on the basic issues for this industry such as definition, philosophy, and the need to develop quality indicators to measure actual quality outcomes and resident satisfaction.

Industry Consumer Education Efforts

Because of the variety of housing and health care options now available, educating consumers to make appropriate long-term care decisions has never been more important for their satisfaction and, by extension, for the industry's ultimate success. The size, building design, types of services offered, rates, and specialty of residences vary widely, offering consumers many options from which to choose.

Helping each consumer to find the residence that best suits his or her needs is the industry's goal. Providing consumers with detailed information on the scope of services and types of fees before move-in is the critical first step. Through ALFA, the industry has developed materials to educate consumers, to enhance the delivery of quality of care and services, and to provide greater consumer protection.

Consumer Awareness and Protection

ALFA's 15-page consumer brochure informs potential residents about assisted living, what it is, the types of services offered, questions they should ask, and a checklist of what to look for when visiting an assisted living community. All of this information and a directory of member residences also is available on ALFA's Web site.

Staff Training

The industry has made great strides to enhance the quality of on-the-job orientation and training while maintaining the flexibility of the worker to provide and assist in a variety of roles in the facil-

ity. To ensure that providers and caregivers have access to quality training designed specifically for assisted living, ALFA has developed an award-winning and comprehensive training curriculum to meet diverse training requirements. The curriculum is industry-specific, underscoring the importance of resident choice, dignity, and independence; builds on the best practices for adult learning; and can be used repeatedly on-site within each residence. Thirty-five of the largest 50 providers in the country have implemented much of the training curriculum, and more than 2,500 residences have invested in it.

Transitioning to an Assisted Living Residence

To help families with their long-term decisions, ALFA has introduced such initiatives as a two-part family video series that will soon be made available to the general public. The videos explore the fears and challenges family members and residents face when making the decision to move into assisted living. Family members and residents recount their experiences and challenges as they moved through this decision-making process to make the transition into assisted living.

Sharing Risk

ALFA is developing a guide to creating shared risk agreements, which help consumers and providers understand the responsibilities and expectations that arise when a resident wishes to engage in activities that are contrary to provider advice. The manual is designed to help both consumers and providers understand the appropriate uses and limitations of such an agreement.

Resident and Family Satisfaction

Resident and family satisfaction surveys are an important tool in measuring quality. Many assisted living operators have developed their own forms and routinely collect this information. In an effort to gauge industry benchmarks nationwide, ALFA also has developed a uniform survey tool called the National Resident Satisfaction Survey, which has been distributed to 30,000 residents, staff, and family members to date.¹

Resident Agreements and Disclosure Forms

To help prevent misunderstandings by clearly communicating services, prices, move-in/move-out criteria, and house rules in understandable language,

ALFA has created two valuable tools for providers to use with their residents. These include a sample Consumer Information Statement and a sample resident agreement. The Consumer Information Statement discloses general information about services and fees to help prospective consumers make a good decision about where to live. Resident agreements are typically required by states and are more detailed. Although the exact requirements may vary, most states require that the agreement address such issues as services available, fees for the services, terms of the agreement, billing and payment procedures, and resident rights. In most states, the surveyor must review and approve the resident agreement prior to issuing a license.

Conclusion

Aging in place would not be possible without the three most important ingredients that make a residence “assisted living,” and which must be thoughtfully and carefully preserved both in provider policies and state regulations.

Above all, assisted living must remain:

- **Responsive to consumer choice and market forces.** The popularity of assisted living as a model has been in the willingness of providers to share the responsibility and, yes, even the risk associated with helping a frail older person who above all wishes to navigate their own destiny without anyone telling them how to do it. We believe the best way to accomplish this is to allow the market to be driven by the consumer.
- **Residential rather than medical or institutional.** Grant assisted living residents all the same rights to age in place that they would enjoy if living in their own individual homes. The desire to control one's living environment, to choose where and how to live, is a very personal matter for Americans. This desire does not simply end when a person turns 82 or requires help with his or her daily needs.
- **Philosophy-driven.** The industry believes the most progressive provider policies and state regulations are those that hold not only basic health and safety concerns to be paramount, but also quality of life and the importance of consumer choice. This goes back to our philosophy of preserving a resident's independence, privacy, dignity, and spirit.

Whether the assisted living setting is a state-of-the-art, newly constructed residence or a small, intimate home, these are the three major premises that have fueled the growth of the industry, revolutionized thinking across the long-term care continuum, and given frail elderly Americans unprecedented freedom of choices for living out the rest of their lives.

Endnotes

1. So far, ALFA has distributed approximately 30,000 surveys to assisted living residents, staff, and family members. To date, more than 8,500 have been returned, thus representing the largest body of satisfaction and related data ever collected and analyzed about the assisted living industry. Another 7,000 responses are expected during the next several months. It is believed that the data from such a large sample will be critical to helping the industry to refine services and contribute to the first progressive, outcome-oriented national satisfaction database.