

**Written Statement of**

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**on Behalf of**

**The National Center for Assisted Living**

**Federal Trade Commission/Department of Justice**

***Hearing on Long Term Care/Assisted Living***

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For the Hearing Record**

Good afternoon. My name is Jan Thayer, and I am President and CEO of Excel Development Group located in Lincoln, Nebraska. My company oversees the management of 14 assisted living and retirement facilities in Iowa, Kansas and Nebraska. We have also developed hundreds of affordable housing units in those states.

In my 20 years of providing long term care to our nation's seniors, I have owned and operated nursing homes and assisted living facilities and have consulted on many occasions for my colleagues in long term care.

I am a registered dietitian and a licensed nursing home administrator. I am an active leader in numerous professional organizations, including the American Dietetic Association. I serve on the Board of Directors of Nebraska Health System and was appointed a member of the Nebraska Health Care Council by Governor Mike Johanns. Currently, I am serving my second term as Chair of the National Center for Assisted Living (NCAL) and I am speaking here today in that capacity.

As part of the American Health Care Association (AHCA), NCAL is the independent assisted living voice of more than 2,300 proprietary and non-proprietary assisted living and residential care facilities nationwide.

NCAL is committed to fostering responsible growth in assisted living and ensuring seniors have access to quality assisted living services and information. We accomplish this by supporting responsible public policies, providing professional education and development services, and serving as an information resource for consumers, the media, and state and federal policymakers.

### **Understanding Assisted Living**

When we talk about long term care in our country today, it is important to understand the diverse array of services and settings that are available. It's not just assisted living and nursing homes. Many seniors utilize home care, receiving personal assistance and/or health care services in their own homes. Some attend adult day care centers on weekdays and live with their families at night and on weekends, while others live in larger independent living communities where only minimal services such as activities and transportation are available. Some people choose to live on campuses where some or all of these settings and services are available and some choose to live in small residential homes with just a few other residents. These options are important to understand because people frequently use a variety of services as they age, not one single service. Assisted living is one of the newer and popular options.

Based on a Scandinavian model for senior living, assisted living first emerged in America during the mid-1980s. Unlike other medical models found in most health care settings, assisted living is based on a social model of care, which translates into a holistic approach toward serving residents. Independence, autonomy, privacy and choice are words that describe assisted living and are the concepts that have made assisted living so popular with the public. People living in assisted living residences receive help with common daily activities so they can retain their sense of individuality and belonging in their communities.

Assisted living emerged as an option for older Americans in response to market demands for a residential setting in which an individual could receive assistance while exercising maximum independence and choice. Another factor steering consumers to assisted living is the

rigid approach of nursing home regulations – and the extent to which these regulations can minimize individual choice by taking a standardized approach to delivering care. Seniors today want flexibility and choice. They want to match their housing options to their medical and social needs as well as their lifestyles and values. Assisted living is a reflection of that consumer desire and behavior.

There are approximately 36,000 state-licensed assisted living facilities housing approximately 900,000 older Americans and individuals with disabilities. While states vary in their approach to regulating assisted living, most have comprehensive regulations in place and 29 states report that they are modifying and updating their existing regulations. I'm attaching a copy of NCAL's 2003 state-by-state summary of assisted living regulations for the record.

Construction of new residences has naturally slowed in recent years as the marketplace has filled. Facilities vary in size and typically consist of 40 to 50 units, but many facilities are much smaller and house only a few residents. The average annual cost to live in an assisted living community is about \$26,000 but varies depending on the available services and amenities, apartment size and facility location, whether urban or rural.

The typical resident is a woman in her 80s, although 31 percent of all assisted living residents are male. She most likely is widowed and lives within 10 miles of a family member. On average, assisted living residents receive assistance with 2.25 activities of daily living, such as bathing, dressing, eating, toileting, and transferring. Nearly half of all assisted living residents lived at home prior to moving into the facility, while nearly one-third came from another assisted living facility, nursing home or hospital.

My following comments address the various topics you raised in the questions contained in your hearing description. I will then be pleased to answer any questions you may have.

### **The Distinction Between Nursing Homes and Assisted Living Facilities**

You asked that I address the differences between nursing homes and assisted living facilities or assisted living residences (ALRs) as they are frequently called. Multiple factors can determine whether a consumer chooses an assisted living setting or a nursing home. Both settings offer assistance with activities of daily living such as eating, bathing, dressing, toileting and transferring. Both settings also offer varying degrees of health-related services but it is the level, intensity and frequency of health-related services that often differentiate an ALR from a nursing home. ALRs typically house about 40 to 50 people on average while nursing homes generally are about twice that size. Most assisted living residents live in a studio, one-bedroom or two-bedroom apartment.

Generally speaking, nursing facilities provide more intensive medical services than assisted living facilities and nursing facilities typically have more licensed nursing staff. The amount of assistance individuals receive in their activities of daily living is a common measure of resident acuity in long term care settings. Assisted living residents need help with an average of 2.25 activities of daily living whereas nursing home residents need help with an average 3.8 activities of daily living. Nursing homes and assisted living facilities differ by the nature and amount of care provided based on resident needs.

Another difference is in how services are paid for. About two out of three nursing home residents rely on the Medicaid program to pay for their care, while another 10 percent rely on the

Medicare program. Conversely, only about 10 percent of assisted living residents receive assistance through government programs (typically Medicaid and SSI).

### **The Assisted Living Workgroup**

Any discussion of assisted living must be prefaced by mentioning a new report about assisted living quality that recently was presented to the U.S. Senate Special Committee on Aging. In 2001, the committee – then chaired by Senator John Breaux (D-LA) – asked assisted living stakeholders to develop recommendations designed to ensure more consistent quality in assisted living services nationwide. As a result of this request, the Assisted Living Workgroup (ALW) was formed with nearly 50 organizations representing providers, consumers, long term care and health care professionals, regulators and accrediting bodies. Meetings began in fall 2001 and a report titled *Assuring Quality in Assisted Living: Guidelines for Federal and State Policy, State Regulation, and Operations* was presented to the committee on April 29, 2003. Many of the recommendations adopted by the ALW related to consumer protections will be referenced today.

### **Disclosure of Consumer Information**

Perhaps more than any other issue, disclosure of information to consumers has received more attention from assisted living professionals during the last few years. In 1999, the General Accounting Office (GAO) found that some assisted living providers were not disclosing all the information deemed important for consumers to make informed decisions when choosing an assisted living community.

The assisted living profession took this criticism seriously, and there was a concerted effort to improve the way the profession approached information disclosure. We became more sensitive to the consumer's right to certain information and bolstered the amount of information we provide. We also encouraged consumers to ask specific questions when selecting an assisted living facility.

NCAL makes available free of charge to the public several consumer brochures, including a comprehensive brochure about choosing an assisted living facility. I'm enclosing a copy of that brochure for the hearing record. Our Web site at [www.longtermcareliving.org](http://www.longtermcareliving.org) contains this free consumer brochure and many others. NCAL also conducted a media campaign about the brochure to increase public awareness about how to choose an assisted living facility.

We also increased our educational efforts for staff. An example of NCAL's commitment to educating those in the profession was the 2001 release of our publication "The Power of Ethical Marketing," which I am submitting for the official record for today's hearing. This brochure provides practical advice to assisted living staff about ethical marketing practices and outlines the specific role all staff play in communicating useful information to both current and prospective residents. To date, we have distributed more than 10,000 copies free of charge to staff in assisted living settings and will continue to do so.

As a result of these efforts, and the efforts of other trade associations representing assisted living, awareness of the need for full and accurate consumer disclosure has risen dramatically. This has been an enormously positive development for residents, prospective residents, their families and the assisted living profession.

Assisted living is regulated at the state level. A recent report by the National Academy of State Health Policy found that 29 states currently are revising and updating their assisted living rules. States vary in their approach to consumer disclosure. Some states have specific disclosure

forms that must be completed and provided to a prospective resident, while others list the information that must be disclosed to consumers.

The ALW report sheds light on the various types of information assisted living providers give to consumers. For instance, one recommendation states that all information conveyed by an assisted living residence to prospective residents – such as marketing materials, sales presentations, and tours – should be consistent with contracts.

Additionally, there is a recommendation that states should require specific, comprehensive, straightforward information in a contract or residency agreement. These contracts or agreements are similar to leases and establish the obligations between provider and consumer, making the document extremely important in the purchase of assisted living services. In addition to marketing materials, contracts generally contain much of the information about a facility and its available services. To illustrate the types of information contracts contain, I direct you to the ALW report's Recommendation R-04 and the contract provisions identified by the group, including:

- The term of the contract;
- A comprehensive description of the assisted living residence's billing and payment policies and procedures;
- A comprehensive description of services provided for a basic fee;

A comprehensive description of and the fee schedule for services provided on an a la carte basis -- or as part of a multi-tiered pricing system that are not included in a basic fee;

The policy for changing the amount of fees;

How much advance notice the ALR will give before changing the amount of fees – for example, 30 days, 60 days or more;

Notices should be readable and understandable by the resident;

Whether the ALR requires an entrance fee, security deposit, and/or other fee(s) at entry, the amount of those fees and/or deposits and the policies for whether or not fees and deposits are refundable and procedures for refunding those fees and/or deposits;

A description of the circumstances under which residents may receive a refund of any prepaid amount such as monthly rent;

- A description of the ALR's policy during a resident's temporary absence;

The process for initial and subsequent assessments and the development of the service plan based on these assessments, including notification that the resident has the right to participate in the development of the service plan;

A description of all requirements for assessments or physical examinations, including the frequency and assignment of financial responsibility for such assessments and/or examinations;

An explanation of the use of third party services (including all health services), how they may be arranged, accessed and monitored (whether by the resident, family or the ALR), whether transportation is available if the services are not provided on-site, any restrictions on third party services, and who is financially responsible for the third party services and transportation costs;

- A description of all circumstances and conditions under which the ALR may require the resident to be involuntarily transferred, discharged or evicted, an explanation of the resident's right to notice, the process by which a resident may appeal the ALR's decision, and a description of the relocation assistance (if available) offered by the ALR;
- A description of the ALR's process for resolving complaints or disputes (including any appeal rights), and a list of the appropriate consumer/regulatory agencies (if applicable, e.g. appropriate state/local long term care ombudsman program, the state regulatory agency, the local legal services program, and other advocacy bodies/agencies);

A description of the procedures the resident or ALR must follow to terminate the agreement.

### **Defining Quality and the Availability of Quality Information to Consumers**

As I mentioned, assisted living focuses heavily on the needs of the individual resident. Understandably then, each resident could determine the nature of "quality care" and "quality service" differently. This explains why assisted living does not have a one-size-fits-all model of care. Facilities and the services they provide vary from state to state and can vary within a state. These variances are due in part to differences in state regulations; however, the greatest factor is the variety in consumer preferences. Any notion that all seniors want or need the same type of facility and services is incorrect. Assisted living grew out of a marketplace need for flexibility and is popular because of its ability to adapt to individual consumer needs.

Currently, there is no standardized method for assessing quality in assisted living nor has adequate research been conducted to develop one. That is not to say that there is not a need for such research. There is. But identifying the correct assessment measures is not as simple as it may sound. The adoption of existing nursing home quality measures will not result in satisfied consumers of assisted living services. A quality assessment tool for assisted living must take into account the active, independent nature of its residents as well as the more social rather than medical model of care. Adding to the complexity of assessing quality is the fact that seniors' expectations change rapidly as new generations of elderly with different values and behaviors enter the long term care marketplace.

Most states do require that an ALR provide a core set of services. State rules also allow for a full range of other services that an ALR may choose to provide. These differences in facility types could make it difficult to compare, from a quality perspective, one facility to another. For example, one ALR may choose to provide care and services for individuals with terminal illnesses who, with hospice assistance, will pass away in the ALR setting. Conversely, another ALR in that state – perhaps just a few miles away – may choose to provide services only to

relatively healthy individuals who, if their care needs exceed certain levels of assistance, must move to another setting. Consumers want both types of ALRs for different reasons.

Knowing what consumers value and how to measure it is also challenging. For instance, would knowing the number of times that residents fall in a facility – the “fall rate” – indicate to a prospective resident whether a facility is good or bad? Or, would this simply mean the facility has one or several residents with conditions that are associated with a higher incidence of falls? What may be more important information to the prospective consumer is how the facility responds to falls and how quickly. This example illustrates how a clinical indicator may provide interesting information for clinicians or researchers but could be relatively useless to a consumer of assisted living services trying to make a decision.

A factor that must be kept in mind is that assisted living – like some other long term care options – is in the business of supporting and caring for people, not necessarily curing them. In many facets of our society – from academia to government to the marketplace – we tend to avoid issues of aging such as its effects and outcomes. While we can’t stop aging, the very expectation behind many existing measures in long term care is that residents may be able to reverse the clinical effects of aging simply by moving into a long term care facility or getting services at home. Many chronic debilitating diseases and conditions cannot be reversed. Even with the best of care, the individual’s health will continue to decline. It’s unrealistic to expect certain clinical characteristics to improve as the residents grow older. It is also a challenge to provide an environment where residents will feel the greatest satisfaction possible with their lives as they see their physical and cognitive abilities diminish.

States generally conduct regular, periodic surveys to determine if a facility is in compliance with state laws and regulations. By and large, these surveys are based on process measures – not outcome determinations. According to a recently published issue brief, *Using Outcomes Measures in Assisted Living*, prepared by Margaret Wylde, Ph.D. of ProMatura Group (American Seniors Housing Association, 2003), there are currently two types of outcomes measures used by ALRs: resident assessment instruments and satisfaction surveys.

Dr. Wylde identifies several reasons why using a consumer satisfaction instrument as both a consumer report card and as a feedback system to promote quality improvement has the potential for inherent conflict. To this point, when outcome measures are used as “report cards,” it is highly likely that staff will do everything conceivable to influence residents in order to attain the highest scores possible. When outcomes are to serve as a tool to identify areas that require improvement, very candid -- that is, non-influenced feedback -- is essential. Therein lies the potential conflict.

Despite all these challenges, tremendous interest exists in conducting research to identify and test more standardized quality measures for assisted living. Identifying these factors and developing accurate, valid measures is one of the great challenges that providers, consumers, researchers and regulators must address together as assisted living evolves. Several states have explored the use of customer satisfaction and other outcome measures in the assisted living setting – and additional research must be done. One significant recommendation from the ALW report was the creation a new national entity that would assume the role of identifying meaningful outcome measures as one of its duties.

## **Risks of Process-Based Measures of Quality**

In general, states conduct periodic surveys to determine if an assisted living facility is in compliance with state laws and regulations. NCAL advises consumers to ask for copies of state inspection reports when shopping for assisted living facilities. We offer this advice because it is the best advice that can be given to consumers at this time.

Some measurement of process does have value. As a dietician I know that following particular guidelines for storing and preparing food dramatically decreases the risk of food-related illness. Proper food handling by a facility clearly warrants assessment and disclosure. Yet, customer satisfaction measures are also relevant, but different. Food can be prepared correctly, but if residents don't like the menu, they are not going to be pleased with what is being served.

Most existing state inspections focus on compliance with various process-oriented measures. Process-based measures determine how something can be accomplished but not whether, or how successfully, it was accomplished. One of the greatest risks of relying on and disclosing process-based measures of quality, particularly in assisted living, is that there is no evidence-based research supporting "best practice" methods for care. That is not to imply that assisted living providers are not using recommended practices. They are. What it reveals is a lack of research linking these practices to expected outcomes.

The philosophy of assisted living involves providing the resident as much choice and flexibility as possible. The resident of an ALR should be an integral part of developing his/her service plan, which outlines what services or assistance a resident will receive and when. Because residents retain the right to refuse services that might be considered "clinically appropriate," the end result may be that the resident's physical health declines more rapidly than if they had allowed certain care to occur. Still, the resident has made an informed and deliberate choice to refuse that particular care or service – and that refusal is an important dignity issue for this resident. A simple example is that of a resident who has a tendency to fall when wearing heeled dress shoes when she dines, yet chooses to continue wearing the shoes, understanding this exacerbates her risk of physical injury.

This simple example illustrates the dilemma facilities can face – and the extent to which choice and personal flexibility impact care. For example, the clinical approach would say quality is defined by taking the heeled dress shoes away and preventing the fall. A quality of life approach might say quality occurs when the facility honors the resident's wishes and personal lifestyle choice even though she increases the likelihood of physical injury. The answer is highly subjective and not easily discernible. At the end of the day, it is likely that either answer could be correct depending upon the resident's values, customs, socialization and the importance of this decision on the resident's perception of herself. This variability makes accurate measurement more difficult.

Ultimately, it will likely be a combination of some process-oriented measures and some outcome measures that will be used to measure quality in assisted living. The obvious challenge is finding the right combination for assisted living and other long term care models.

## **Competition's Impact on Quality Measures, Costs, Prices and Decisions**

Currently, there is a high level of competition among assisted living providers in most markets – and that competition is as beneficial to assisted living just as it is to every other facet of our nation's health care system. The assisted living field is sensitive to marketplace forces such as costs, services, amenities and customer satisfaction.

It is important to remember that the predominant payor of assisted living is the assisted living resident – and/or family members. As such, it is primarily seniors on fixed incomes who live in assisted living. Medicaid plays a small role in paying for assisted living services while Medicare does not pay for assisted living. Because resident and government resources are limited, we must be cautious and not let our methods for measurement define our services instead of our residents. Some quality measures could potentially increase costs depending on what is measured, how it is measured, how often and by whom. We must consider these factors and avoid costly measurements that yield little helpful information.

### **Information Consumers Need to Make Well-Informed Purchasing Decisions**

Consumers should not be lulled into thinking that choosing a long term care facility is as easy as comparing a set of measures (no matter how many or what types of measures) from different facilities. Choosing the right facility is a complex process. Consumers must take the time to visit several facilities, ask many questions of staff, residents and families, review contracts and materials, and observe interactions between residents.

Choosing an assisted living facility requires a lot of involvement by the consumer and family member. This process involves the choice of home and staff who will provide daily services to them. In an era when we purchase items with the click of a mouse, we must not lose sight that assisted living is a people-oriented service that requires first-hand observation of the staff and facility environment. These are, by far, the best indicators of whether a consumer will make the right choice.

We also must keep in mind that each consumer has different priorities about what he or she determines to be important attributes of a facility. In the final analysis of selecting an ALR, each consumer must clearly understand what specific services are offered, how much those services cost and the conditions under which he or she may have to move if care needs exceed the capacity of the ALR.

The best way to help consumers make the right decision when choosing an assisted living facility is to help them identify what is important to them, and then provide them with the information and questions they need to ask staff in the prospective facility to determine whether the facility is a good match.

Assisted living is a relatively new form of long term care service and still evolving. As a profession, we are committed to continuously looking for ways to improve our services, meet our residents' expectations, measure our work and provide prospective customers with the information they need to make sound decisions. I would be pleased to answer any questions.

Thank you.

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