

Chairman Craig, Senator Breaux, and members of the Committee, thank you for the opportunity to speak with you today about what I believe is one of our nation's most important long term care concerns. I am here today on behalf of the Consumer Consortium on Assisted Living (CCAL). We commend you for taking up this timely topic again following this Committee's important hearing on assisted living in 1999.

BACKGROUND

CCAL, established in 1995, is the only national, consumer-focused organization dedicated solely to the needs and rights of assisted living residents. I have been an administrator of several assisted living facilities ranging in size from 60-beds to a 220-bed campus. I co-founded CCAL and currently serve as Co-Chair of the Board of Directors. I am joined in the audience today by CCAL's Executive Director, Bill Benson. Additionally, I am a consumer. My father has Alzheimer's disease and has resided in an assisted living facility for over two years.

CCAL heartily supports assisted living as a vital option for long term care services. However, **CCAL does not support caring for America's frail elderly in assisted living without defining and specifying what appropriate care is and without assuring its provision through national standards.** Our country, perhaps inadvertently, is placing a very vulnerable population at an extraordinary risk. The tremendous growth of this industry runs the risk of overriding our commitment to the care and protection of this vulnerable population.

An estimated 1.0 million elderly currently reside in assisted living. Compare this to the estimated 1.5 million residents of nursing homes, an industry that has been around significantly longer than assisted living, and one understands the explosive growth occurring in this relatively new long term care option. The U.S. Bureau of the Census projects that the population of individuals 85 years and older will be the fastest growing part of the elderly population throughout the rest of this century, and will more than double by 2030. This enormous growth has significant implications for the assisted living industry as individuals 85 years and older are those most likely to become assisted living residents.

At times, the rapid growth of the industry has occurred at the cost of resident care as quality resident services have not kept pace with "bricks and mortar" construction. The average assisted living resident is an 84-year old frail female. Catherine Hawes, PhD, author of the U.S. DHHS funded National Assisted Living Study, found that one in four assisted living residents needs as much help as a typical nursing home resident. Yet despite the tremendous growth of the industry and the frailty of its residents, there are **no uniform standards or federal regulations** to protect residents.

FACTS

In a sobering report to this Committee two years ago, the General Accounting Office (GAO) noted that the lack of uniform standards forces consumers to rely primarily on providers for information about assisted living. The GAO found that providers do not routinely provide consumers with the information necessary to select the setting most appropriate to meet their needs. CCAL has found that some marketing literature continues to be misleading (such as showing pictures of staff in lab coats with stethoscopes when, in fact, the facility does not provide healthcare), or incomplete, (such as not fully describing costs and eligibility, requirements for different levels of care, or what happens when a resident's finances are exhausted or when he or she becomes seriously ill or disabled).

Other frequently cited problems identified in the GAO report include: **inadequate or insufficient resident care; insufficient, unqualified, and untrained staff; and inappropriate medication**

administration. One recent caller to our Helpline described a situation in which her father has lived in an assisted living facility for over three years. This caller described her father as needing assistance daily with basic care needs such as bathing and dressing. Her father often goes without assistance because there are not enough staff. As a long time resident, he has bonded with the staff and residents and is willing to accept poor care in lieu of moving somewhere else where he does not know the staff or residents. This creates serious conflicts for the daughter because she hates to see her father poorly care for, yet she understands his need to fit in as well as his ability to make his own decisions. Dr. Hawes recently found that 25% of the more than 300 assisted living facilities she studied had only one caregiver for every 20 residents in the 3-11 shift and one for every 34 at night. According to a statement Dr. Hawes made last year, the combination of sicker people and low caregiver-to-resident ratios is dangerous. "These two things are on a collision course - it's just a time bomb waiting to go off."

We fear that in the two years since the Committee's last hearing the time bomb may have already gone off. Recent front-page articles in *The New York Times*, *The Washington Post*, and *Wall Street Journal* abound with stories of problems in assisted living facilities. *The Washington Post* reported that an 83-year old frail female resident residing in a facility of one of the industry's largest providers was assaulted in a day room by a male resident with a psychiatric history. This vulnerable resident died two days later in a hospital from injuries sustained in the assault. Was this male resident an appropriate admission to a facility caring for vulnerable individuals?

Not only are catastrophic events for some residents and their families continuing, but in the last two years, a dearth of workers in the long term care industry and low occupancy rates pressuring the need for providers to fill beds have further heightened concerns about quality care for the vulnerable consumers of assisted living.

STATE REGULATION

These significant problems are compounded by an uneven and patchwork approach to state regulation and oversight thus producing an increasingly alarming picture of the assisted living industry. The assisted living industry is regulated individually by states and predominantly funded by private resources. **State standards are highly variable, and the variability begins with the very designation of the name 'assisted living'.** Broadly defined, assisted living can be described as a residential care alternative to nursing homes that allows people to "age in place" while receiving services to help them retain their dignity and preserve and enhance their autonomy. States, however, use over two dozen designations even to refer to what is commonly known as assisted living, for example: California - residential care facilities; New Mexico - adult residential shelter care facility; New York - assisted living program, adult care facility, adult home, and enriched housing program; and Michigan - home for the aged and adult foster care.

This lack of any consistency or uniformity in definitions can create great confusion and poor outcomes. For example, both New York and Michigan have many facilities that fall into none of the categories in existing law, meaning they do not have to be licensed. These unlicensed facilities include some that are owned by some of the nation's biggest assisted living operators. Alterra Healthcare Corporation, the nation's largest operator of assisted living facilities, for example, has 19 homes in New York State. Half of these facilities are unlicensed despite a claim by their President and CEO, who is quoted in the November 26, 2000 edition of *The New York Times* as stating "I am proud of the fact that all of our residences are licensed and that we have done that voluntarily". That is simply not true.

The regulatory variances among states are vast. In California, for example, residents may be required to leave a residential care facility if they become incontinent. New Mexico statute has no provisions for a resident bill of rights, admission criteria, contracts, or grievance procedures. In New York there are no

specific guidelines for care of individuals with dementia. In Kentucky, new regulations exempt all facilities that already existed when the new law took effect in July 2000. A Michigan task force on assisted living rejected the idea of stronger state oversight, recommending instead, that the state simply require facilities to sign a clear contract with each person who moves in. Even this poorly conceived proposal has languished.

The processes by which states develop their assisted living regulations also leave much to be desired. For example, the Tennessee Department of Health recently determined that the most expedient way to develop assisted living regulations for their state was to invite leaders from the nursing home and assisted living trade associations together to form consensus on new assisted living regulations. The groups were given the state's nursing home regulations to use as the basis for developing assisted living regulations. Consumers and other advocates were excluded from the process. The state's Commission on Aging was invited to participate, but declined. Unfortunately, this approach is not unique to this state.

The patchwork state regulatory approach is extremely confusing to those with expertise in the assisted living field. Imagine the difficulty faced by consumers who typically must make their placement decisions in the midst of personal crisis.

Is there any industry that would not love the opportunity to police itself? By default in some states, and by a patchwork of regulations in other states, this is in effect happening all too often in the assisted living industry. According to a founder of Kapson Senior Quarters, a chain of assisted living facilities that is now part of Atria Inc., "the industry is doing one hell of a good job of policing itself". Many consumers, long term care ombudsmen, state regulators, geriatric care managers, elderlaw attorneys and other advocates would beg to differ not to mention the abundance of front-page newspaper stories describing egregious incidents.

"If a consumer does not like a certain facility, they can let their feet vote", is a statement oft heard from leaders in the industry such as two past presidents of the Assisted Living Federation of America. This statement is demeaning to consumers, and does not reflect market or personal realities for consumers. Making a decision to leave a facility that is not providing appropriate care for a resident's needs is not the same as deciding not to return to a certain restaurant because service was poor, or to take your drycleaning elsewhere if prices are increased. The decision to move out of a facility is a last resort decision fraught with emotional, psychological, and financial complications.

MYTHS

Many myths immediately surface whenever there is any discussion about the need for federal regulation or oversight of assisted living facilities. One myth is that there are very few federal dollars spent on assisted living, and therefore the federal government should not be involved in regulating this industry. We all know what would have happened had the tire industry not been subject to any federal scrutiny over tire standards for SUVs. The federal government does not directly subsidize the tire or auto manufacturers, yet they oversee and protect consumer safety needs for both of these industries. Nor has the federal government delegated this important function to individual states. It can be argued that increasing amounts of federal dollars are in fact going to assisted living. More and more states are allowing the use of Medicaid waiver dollars for residents of assisted living. Medicaid is a shared federal-state responsibility with the federal government paying fifty percent of the cost.

Another myth is that federal regulations have not worked to provide quality care for nursing home residents, therefore, this same approach should not be replicated for the assisted living industry. Research has demonstrated that improved quality of care has occurred as a result of OBRA 1987 - the

landmark Nursing Home Reform Law. For example, the use of physical and chemical restraints in nursing homes has dropped dramatically as a result of OBRA 1987. A closer look at nursing home regulations, however, finds that it is not federal regulations that have not supported quality resident care, but rather, too often, the quality of the management and operators of individual nursing homes, as well as uneven oversight by state regulators. Often, when nursing home providers speak of overburdensome regulations, closer inspection reveals that they are speaking of important standards relating to fire safety or sanitation, or outdated state-specific regulations, not standards or requirements in federal law or regulations. Furthermore, when nursing home providers malign the regulatory system, they are often referring to the enforcement process - not the regulations. Good, caring providers and health care professionals working in nursing homes are generally in tune with the national standards for quality of life, quality of care, and resident's rights. In fact, the national nursing home trade associations came to consensus with consumers and advocates on the standards in current law, with the exception of the enforcement provisions and the need for stronger nurse staffing requirements.

Another frequently heard myth is that consumers in each state have their own specific needs and therefore the standards and regulations need to be uniquely tailored to individual states. Through the CCAL Helpline, we hear from consumers and advocates from across the country. It is CCAL's belief, based upon our personal experience with consumers and their families, that consumers, regardless of where they live, have the same concerns about receiving good quality and appropriate care. We live in a highly mobile society where family members and special friends are often scattered throughout the country. It is natural and practical that we want consistency in how our loved ones are cared for.

One last myth - that regulation stifles innovation. Many other industries have been successfully regulated without adversely affecting innovation such as the building industry, auto manufacturers, and pharmaceuticals to name a few. It is the individuals who design and create products and services that affect or limit innovation - not the standards themselves.

ACCREDITATION

ALFA, the largest trade organization of assisted living providers, indicates that it is eager to improve quality, but prefers a new private system of voluntary accreditation that is beginning to inspect facilities and grant a seal of approval. In 2000, both the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the Commission of Accreditation of Rehabilitation Facilities (CARF) began accrediting assisted living facilities. The accreditation criteria are very broad and non-specific. Several examples of criteria include: "The assisted living facility provides safety and security measures to meet the needs of residents"; and "The assisted living community provides services for each resident according to accepted standards of practice and law and regulation." Both organizations refer to their accreditation criteria as 'standards'. Rather than setting definite requirements, these 'standards' set out general objectives that are meant to focus on continual quality improvement. **These 'accreditation standards' would more accurately be defined as quality improvement tools.** They cannot be equated with or considered to be specific, uniform and measurable standards. In effect, they can only be measured with a "yes" or "no" response. Can any of us imagine a facility answering "no" to the sample criteria noted above? Unfortunately, in the absence of any consistency in assisted living standards, these new accrediting programs can serve to further confuse assisted living consumers about what defines and connotes appropriate resident care.

CONCLUSION

As the aging of America continues to spiral upward, so will the number of individuals residing in assisted living. One of the problems with nursing home oversight and national standards is that advocates have spent decades trying to catch up to an industry that got off to a free-wheeling and

virtually unrestrained start. Our nation's nursing home residents and their loved ones have paid and continue to pay a high price for that. The assisted living industry has been given a virtually unrestrained start as well. CCAL believes no further time should pass before our nation begins to appropriately and responsibly address the serious conditions that have developed in assisted living. **From urban to rural locale, from coast to coast, from provider to provider, our nation's frail elderly need uniform standards that define and provide guidance and protections to consumers.**

We at CCAL feel so strongly about this that we have initiated an effort to develop model standards for assisted living. I am delighted to say that the American Bar Association's Commission on Legal Problems of the Elderly has agreed to join us in this effort. The National Citizen's Coalition on Nursing Home Reform also supports this initiative. While we believe there should be national standards -- and that in time there will be national standards -- we can help now by offering a set of model standards. Our hope is that at minimum, individual states will agree to adopt our model standards, and that progressive industry leaders would adopt them for their own facilities. We hope that the industry will join us along with many others who are stakeholders in assisted living in developing these standards.

Thank you again for the opportunity to appear before the committee today.