United States Senate, Special Committee on Aging

Ensuring Quality and Oversight in Assisted Living

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Chairman Kohl, Senator Corker, Senator Nelson, thank you for the opportunity to testify before the United Sates Senate Special Committee on Aging.

LeadingAge (formally AAHSA) represents almost 5,700 not for profit members who provide care and services to over one million seniors on a daily basis. Our members provide the full range of long term care supports and services, from intensive skilled nursing care to community based services such as adult day services and meals on wheels. Many of our members provide services which would fall under the broad category of assisted living and I am here today to provide the perspective of our members and other assisted living providers on the issues the committee is exploring.

First and foremost, I want to state that while I am not personally familiar with the circumstances of the events detailed in the articles by the Miami Herald, members of LeadingAge and all assisted living providers across the country were horrified to read the examples of the terrible care cited in the articles. I can assure you the vast majority of assisted living providers work very hard to provide excellent care to the residents they serve and the circumstances cited in the article are the rare exception to the care provided across the country.

I would like to address two issues that the articles raised, quality of care and consumer disclosure in assisted living, as well as the issue of Medicaid waivers in assisted living.

The term “assisted living” is one that has no consistent definition across the country, but generally it is thought of as care to seniors who need assistance with activities of daily living, bathing, dressing, toileting, transfers, personal hygiene and ambulation. Frequently there is some form of assistance with medication management. Every state has a licensing scheme for assisted living, although in some cases it is not referred to as assisted living, but rather terms like boarding home or board and care. The level and types of care each state allows in assisted living can vary, but there is an increasing trend of allowing assisted living communities to provide significantly higher levels of care than 10 or 15 years ago either by providing services directly or by allowing outside providers such as home health care agencies to offer services in the assisted living community.

LeadingAge and providers in general believe this is not solely a matter of avoiding the much higher cost of nursing home care, but more a recognition that consumers choose to live in assisted living communities. These communities are their homes and they want to live there as long as possible and age in place.

As assisted living has become a larger player in the array of long term care services for seniors, the efforts to improve care have increased as well. The information, educational opportunities and resources available to assisted living providers are far greater than I could begin to list. However, I would like to highlight a few.

The provider associations have long been working with their members to provide them with education, resources and tools to improve care and services. LeadingAge's own "*Quality First*" is an example. "*Quality First*" is a comprehensive plan many of our members use to help establish and maintain excellence in care and services, it is our effort to achieve excellence and earn the public's trust. Detailed information is available on our website, www.LeadingAge.org.

Other examples of resources for quality improvement are the National Center for Assisted Living's (NCAL) " *Guiding Principles for Assisted Living*" and "*Quality and Performance in Assisted Living*" which has a wealth of information including clinical practice guidelines for assisted living on their website, www.ahcancal.org. The Assisted Living Federation of American (ALFA) has developed "*Core Principles*" along with other resources for its members which are available on their website, www.alfa.org.

I would be remiss and would incur the wrath of my fellow board members if I didn't also highlight The Center for Excellence in Assisted Living (CEAL). CEAL is an outgrowth of the efforts of this committee ten years ago which resulted in the Assisted Living Workgroup report and the formation of CEAL in 2004. CEAL is comprised of 11 stakeholder organizations (AARP, Alzheimer's Association, American Assisted Living Nurses Association, American Seniors Housing Association, ALFA, Consumer Consortium on Assisted Living, LeadingAge, NCAL, NCB Capital Impact, Paralyzed Veterans of America, and Pioneer Network) all of

whom have representatives on the Board of Directors. I serve as the LeadingAge representative and was the Board Chair in 2010. CEAL also has an Advisory Council of 27 stakeholder organizations, federal agencies and individuals which serves as a resource for CEAL.

The mission of CEAL is to foster high quality assisted living by bringing together diverse stakeholders to bridge research, policy and practice; facilitate quality improvements in assisted living; identify gaps in research and promote research to support quality practices; and promote access to high quality assisted living for low and moderate income seniors. The accomplishments of CEAL over the last seven years are too numerous to list but they include establishing an Information Clearinghouse that has almost 800 discrete items on almost every aspect of assisted living; developing the Excellence in Assisted Living Awards in 2009 to highlight and disseminate best practices in five different practice areas; developing a pocket guide for caregivers on medication administration and developing a pocket guide for infection control just released this month; and publishing "*Person Centered Care in Assisted Living: An Information Guide*" last summer. For more informational on CEAL please go to its website, www.theceal.org.

Lastly, I should also point out there are resources directed at the consumers of assisted living services, the residents and their families. One great example is the Consumer Consortium on Assisted Living, CCAL, which focuses on helping the consumer in learning about and making choices for assisted living. Their website, www.ccal.org, has a huge amount of information all geared to the consumer.

My purpose in mentioning these organizations is simply to provide you with a small sample of the tremendous amount of information and educational materials available to assisted living providers. There are numerous other associations and groups who provide material for both the provider and consumer. The vast majority of assisted living providers take advantage of these resources as they continue to meet the needs of the residents they serve.

I would suggest the use of these resources may have prevented the quality of care issues raised by the Miami Herald. While I recognize this committee and other

elected officials may look to more regulation to address the bad acts of the providers exposed by the Miami Herald, I urge the Committee and others not to look to more regulation, but rather to continue to promote these resources to providers. For those few providers who do have quality of care issues, state licensure officials should use the authority they already have to require poor performing communities to seek and implement the programs and resources they need to raise their level of care to that of the rest of the assisted living providers.

Now I am not naïve enough to suggest that there isn't a major role for regulatory oversight of assisted living. It already occurs in all 50 states and LeadingAge, NCAL ALFA and ASHA support state regulations. I also recognize that there are occasional quality of care concerns in assisted living in all parts of the country. In my previous life representing assisted living providers I saw the vast majority of good providers, but also the occasional poor performing provider. What I am saying is that my experience and the experience of many in the long term care services and supports sector have not seen additional regulation as the best way to improve quality of care.

Last spring, this Committee had a roundtable on assisted living. While many issues were discussed, it was clear from the representatives from the states of Tennessee, Arkansas, Oregon, Alabama and Wisconsin that they strongly believed the assisted living providers in their state provided high quality of care and they had a strong regulatory system that protected consumers. I think you will find that true in the other states as well. The excellent care provided in assisted living communities across the country bear this out. Maintaining this level of care will come from providers in conjunction with state regulatory agencies tapping into the resources available to promote and maintain the high quality of care we have come to expect from assisted living providers in all parts of the country.

Turning to consumer awareness and disclosure, there is clearly a need for increased sources for consumers to understand what assisted living is and is not, as well as understanding which assisted living provider may be right for them or their loved one. Assisted living is a relative newcomer in the system of long term care. There was tremendous growth from 1990 until the recession and many

people are not really sure what assisted living is. They often lump it in with nursing homes. States are taking significant steps to address consumer issues; 37 states have some form of disclosure statement or requirement for the assisted living provider to make information available to prospective residents and their families; 49 states have regulatory requirements for residency agreements mandating they contain certain consumer protections, although disclosure and residency agreement requirements vary from state to state.

Several states have web based information on their assisted living providers and I believe this will continue to increase. Many of the organizations I mentioned above, especially CCAL, have information for consumers to help educate them on what assisted living is and how to choose an assisted living provider. There are also an increasing number of private companies that have web based listings such as SnapforSeniors and NewLifeStyles. Consumer education about long term care services has always been difficult. It is care setting we don't want to think about and don't usually face until we have to, often in an unexpected and emotional situation. This is one area where providers, state regulators and agencies like the U.S Administration on Aging and the Office of Long-Term Care Ombudsman Programs could work together to find ways to increase consumer awareness. Better educated consumers are in everybody's interest and are something the provider community strongly supports.

An example of this kind of effort is the Assisted Living Disclosure Collaborative that the Agency for Healthcare Research and Quality launched 3 years ago in conjunction with CEAL. This collaborative brought together almost 30 stakeholders and technical experts in an effort to create a uniform disclosure "tool" which could be used by consumers, state agencies and others to inform consumers about the services provided at an individual assisted living provider. The goal is to have an easy to understand method to compare the services and amenities of one assisted living community to another in a standardized format. The disclosure "tool" has been developed and will be undergoing field testing in eight states and in over one hundred communities after OMB clearance. After testing, the disclosure tool will become available for use.

Lastly, I will comment on the currently pending Proposed Rule for the Medicaid Program's Home and Community Based Services Waiver Program under 1915 (c) of the Social Security Act. There are two aspects of the proposed rule which have created concern among assisted living providers. First is the proposal to allow states to combine waivers of all three targeted groups into a single waiver. The second is what standards The Center for Medicare & Medicaid Services, CMS, will use to determine whether a provider meets certain criteria defining home and community based services (HCBS).

In reading the Miami Herald articles it is clear that some of the residents in assisted living communities cited in the articles had diagnoses of mental illness. I am not raising this in any way to suggest that the standards for care for persons with disabilities should be any different from that of frail seniors. Rather it is to point out that LeadingAge and other provider organizations raised concerns about a provision in the proposed rule allowing states to combine the three current waiver categories, aged or disabled or both, mentally retarded or developmentally disabled or both, or mentally ill, into one waiver.

LeadingAge supports giving states more flexibility in the waiver program, but combining waiver programs could have the unintended consequence of creating competition for limited waiver money among the three groups and potentially lead to placements in settings inappropriate for the individual. Each of the target groups has very distinct and separate care needs and challenges and we are concerned that a combined waiver may result in one of the groups receiving less funding and possibly placements not in the best interest of individuals.

In the Proposed Rule, CMS proposes several criteria in the rule itself as well as in the Background Comments to the rule to define what CMS will consider as an appropriate home and community based setting. LeadingAge and other provider groups, including NCAL, ALFA and American Seniors Housing Association oppose these provisions because they would effectively prevent assisted living communities and other providers from participating in the waiver program. Without going into detail, there are criteria in the proposed rule related to the location of the HCBS provider as well as prohibiting waiver money from being

used in settings designed around a person's disability or diagnosis. In the background comments there are criteria related to leases, sleeping/bathing/cooking areas in a dwelling, lockable doors, and visitation times among others. All these criteria are attempts to somehow differentiate providers who are providing resident centered home-like settings from ones that are perceived to be "institutional" in nature. LeadingAge submitted comments on the Proposed Rule and contends CMS is missing the point of resident centered home-like care.

LeadingAge believes CMS should focus on the program and services of a provider, not criteria related to physical plant or location. The attributes of resident centered care are adaptable and applicable to any kind of living setting and, conversely, the type of setting is no guarantee of resident centered home-like care. Any setting could provide wonderful home-like care and any setting could have a program that inhibits and restricts resident choice and involvement in their care. The Proposed Rule has a section on person centered planning which LeadingAge supports and believes should be the focus of the rule, not the arbitrary criteria which will effectively exclude many current community based providers.

Thank you for the opportunity to provide testimony on these important topics.