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ENSURING QUALITY AND OVERSIGHT IN ASSISTED LIVING

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ENSURING QUALITY AND OVERSIGHT IN ASSISTED LIVING

WEDNESDAY, NOVEMBER 2, 2011

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The Committee met, pursuant to notice, at 2:03 p.m. in Room SD–G50, Dirksen Senate Office Building, Hon. Bill Nelson, presiding.

Present: Senators Kohl, Nelson [presiding], Whitehouse, Manchin, and Corker.

OPENING STATEMENT OF SENATOR HERB KOHL, CHAIRMAN

The CHAIRMAN. Good afternoon, and we thank you all for being here today. We're very pleased to have Senator Bill Nelson, a longtime member of this committee, chair this hearing. He's a committed and hard-working member of this panel. Senator Nelson's great state of Florida is home to the largest number of seniors in our country and a leader among states in trends that shape long-term care, including assisted living.

We've also paid a great deal of attention to long-term care in Wisconsin. In fact, two years ago, we reached a point where the number of people living in assisted living residences exceeded the number living in Wisconsin's nursing homes. More and more older Americans are looking for options that let them stay within their community and allow them to remain as independent as possible for as long as possible.

Recognizing the growing importance of assisted living, the Aging Committee hosted a roundtable in March when Senator Corker and I gathered 19 talented experts to discuss a wide range of topics, including ways to address the need for more affordable assisted living and how to deal with consumers who can no longer afford to pay for their care. So this afternoon, we're looking to this panel to help us craft solutions in two key areas, quality assurance and oversight.

Assisted living encompasses a large variety of residential options and levels of care that vary from state to state and even within states. Despite the many differences, we need some level of consistency in the quality of service and safety standards that all providers should be expected to meet.

We also need to understand how best to enforce these standards and at what level of government. And we need to provide much more transparency about quality and foster a better dialog between

residents, their families, and providers so that tragedies like the one that Mr. Navas will relate are prevented.

We look forward to hearing from all of you, and we thank you again for coming. With that, I turn to my very good friend and a great, great senator, Bill Nelson, who has been deeply involved in this very important issue.

Senator Nelson.

STATEMENT OF SENATOR BILL NELSON

Senator NELSON [presiding]. Mr. Chairman, thank you, and thank you for giving me the privilege of chairing this hearing today on an extremely timely topic, Ensuring Quality and Oversight in Assisted Living.

This spring, the Miami Herald—it had a three-part series, "Neglected to Death." It reported on abuses at several of Florida's assisted living facilities. And the report found that 70 people had died from abuse or neglect since 2002; that 1,732 homes were caught using illegal restraints like ropes, locking residents in closets, and tranquilizing drugs. And the state caught providers falsifying records—and that included medical records—in death cases 181 times.

These stories, unfortunately, are not just limited to Florida. In Pennsylvania, emergency room workers removed 50 maggots from a resident's open facial wound. And in New York, a senior died after caretakers mistakenly gave her someone else's prescription. In Virginia, police responded to a 911 call and found one resident lying on the floor calling for help while another was struggling with a catheter.

Now, it doesn't mean that assisted living facilities across the country are failing. I know of many in my state that are honest providers, genuinely caring for residents and operating high-quality homes. And that's what we would hope for any of our family members, and we have high-quality ALFs across the country. But even one case of misconduct is one too many, and both consumers and providers want to prevent these kinds of abuses.

The chairman's Aging Committee has always been very involved in promoting quality in assisted living. In 2001, this committee examined the role of assisted living in the 21st Century, and it focused on consumer protection, staff training, and assistance with medications.

And after that hearing back in 2001, a group of nearly 50 national groups representing providers, consumers, long-term care professionals, and regulators came together to develop recommendations on improving the quality and presented those recommendations in 2003. And just this year, Chairman Kohl and Ranking Member Corker organized a roundtable, as the chairman had mentioned, of 20 assisted living professionals to tackle three major issues facing us today—quality, affordability, and creating aging in place environments—so older and disabled adults could continue to live independently.

So it's fitting that we're here today to continue this important discussion and to turn our focus to quality and oversight. About 1 million Americans make their home in assisted living, and among that is about 131,000 Medicaid recipients. Most assisted living is

privately funded, but more and more Medicaid dollars are going to assisted living. Assisted living is growing at a faster rate than institutional care, institutional care like nursing homes. Medicaid participants in assisted living grew 43 percent in the seven years from 2002 up, while nursing home spending only increased about 10 percent.

The federal investment in assisted living will continue to grow as states and consumers look for alternatives to institutional settings. This doesn't only have implications for Medicaid, but there are many indirect costs to Medicare as well. So the people in long-term care facilities often make up a large share of Medicare spending. They have high rates of hospital and emergency room visits. Many of these visits can be prevented if caretakers are properly equipped with the skills and tools they need to serve our seniors.

But how do people know if the assisted living facility they're choosing is properly equipped? How can individuals and their families make the right decision on the best environment? And that's one of the big challenges.

There's no single definition of what an assisted living facility is, and every state regulates them in a different way. And because of this variety, residents and their families often rely on information from the facilities themselves, and every state has different requirements on what kind of information the providers are required to disclose. Some states don't even have any disclosure requirements.

All Americans, no matter what state they live in, should have the tools that they need to make the right choice. So even though this isn't a new issue—and this committee discussed this lack of disclosure back in 2001, and the GAO noted the lack of consumer education in reports going back to 1999 and 2004.

So we're going to have to ask ourselves in this hearing if we've been talking about the same problem for over 10 years, why are we still talking about it? What are the solutions? We all know that disclosure isn't the only solution. And when something goes wrong, folks need to know that their complaints will be heard and that someone will be held accountable.

Every American, no matter what the state is that they live in, should be afforded some basic protections. And most states require that facilities be inspected every one or two years. But there are even some states that it's once every four years. California only requires inspections every five years, and Texas requires inspections when they're deemed appropriate.

Inspection reports are public in almost all of the states, but 23 states only make these reports available upon request. And many states are struggling to inspect more and more facilities with limited resources. So that's what we're going to dig into today, and we're fortunate to have several experts.

The first witness, Barbara Edwards, serves as the Director of the Disabled and Elderly Health Programs Group in the Center for Medicaid and CHIP Services at CMS. Ms. Edwards has almost 30 years of public and private sector experience in healthcare financing and its nationally recognized—she is a nationally recognized expert.

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Ms. Martha Roherty is the Executive Director of the National Association of States United for Aging and Disabilities. And that represents the nation's 56 state and territorial agencies on aging and disabilities.

Dr. Larry Polivka.

Dr. POLIVKA. Correct.

Senator NELSON. Polivka. Well, that's because you're at FSU.

He's the Executive Director of the Claude Pepper Center at Florida State University and was Director of the Florida Policy Center on Aging until 2009.

Alfredo Navas is a resident of Florida and is here to share the story of his mother, Aurora Navas, who passed away due to the negligence at an assisted living facility.

Steve Maag—the Director of Residential Communities at Leading Age, an organization of non-profit, long-term care providers. Mr. Maag is responsible for developing and implementing public policy, including assisted living, continuing care, retirement communities, and senior housing.

And Robert Jenkens is the Director of the Green House Project, a nursing home alternative that offers independence and dignity to residents. He's also vice president at NCB Capital Impact, where he provides policy and development consulting to states and organizations interested in promoting quality assisted living.

So thank you all for being here. We'll just go right down in the order. See if you can confine your comments to five minutes, and then we'll get into a lot of questions.

Mr. Chairman, did you have anything else? Okay.

Please, Ms. Edwards.

STATEMENT OF BARBARA EDWARDS, DIRECTOR OF THE DISABLED AND ELDERLY HEALTH PROGRAMS GROUP, CENTERS FOR MEDICARE AND MEDICAID SERVICES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Ms. EDWARDS. Senator Nelson, Chairman Kohl, Ranking Member Corker, and members of the committee, thank you for the invitation to discuss how the Centers for Medicare and Medicaid Services can support states in offering long-term care options that promote independence and choice and assure that Medicaid beneficiaries have the opportunity to live and fully participate in their communities.

Medicaid is the largest purchaser of long-term services and supports in the nation. State-designed Medicaid programs offer long-term care services to elderly and younger Americans with significant physical and cognitive impairments through both institutional settings, such as nursing homes, and home and community-based settings.

Assisted living facilities are one of many settings in which home and community-based services, or HCBS, may be provided. And assisted living facilities are often identified as providers of HCBS, including personal care supports, homemaker chore services, and assistance with activities of daily living, among others.

Unlike nursing home care, which states are required to provide under federal Medicaid law, state Medicaid programs are not re-

quired to cover services offered at assisted living facilities, even for residents who are otherwise covered by Medicaid. Also in contrast to nursing home services, Medicaid does not cover the cost of room and board in any assisted living facility or other community-based residential setting.

However, the vast majority of home and community-based services are provided under what are called 1915(c)—Section 1915(c) of the Social Security Act, which authorizes the secretary to waive certain statutory Medicaid requirements to allow states to provide alternatives to institutional care. Forty-eight states and the District of Columbia offer services through more than 320 active, home and community-based waiver programs, and the two other states provide similar services through a Section 1115 waiver. So all states are providing home and community-based services to Medicaid consumers.

Defining, licensing, and oversight of most HCBS providers, including assisted living facilities, is largely a state responsibility. CMS does not define what qualifies as an assisted living facility, nor are there federally established conditions of participation in Medicaid, again unlike nursing homes where there is both federal law and regulation with regard to the operation of nursing homes.

Depending on the state, assisted living facilities may take the form of group homes, adult day or foster care settings, or senior living communities. Assisted living facilities, therefore, can vary in the population they serve, in their size, and, as Mr. Nelson was describing, their payer mix. Medicaid is typically not a major participant in the financial support for residents of assisted living facilities.

While there is no specific federal licensure requirements for HCBS providers, Section 1915(c) statute and regulations require that the state demonstrate several assurances regarding its waiver programs, including assurances related to participant health and wellbeing. CMS requires a state to specify the services to be offered through a waiver, identify the qualifications of service providers, and identify the standards required for settings in which care is delivered.

A state must demonstrate that it is prepared to protect participants in a number of ways, assuring that providers and settings meet the specified qualifications set by the state, assuring that individuals receive the services identified in a person centered plan of care, monitoring participant health and wellbeing, and identifying and responding to allegations of abuse that involve waiver participants. In addition, a state must submit a quality improvement strategy that identifies, addresses, and seeks to prevent poor outcomes or abuse and neglect.

To satisfy federal monitoring requirements, states must submit evidence that they are meeting the assurances, including a final report in the year prior to the expiration of the state's three or five-year waiver period. Continuation of a waiver requires a determination by CMS that the state has met the waiver assurances and other federal requirements.

At present, if CMS identifies serious quality issues, such as potential harm to the health and wellbeing of waiver participants, CMS can conduct special onsite reviews, offer technical assistance

from a national quality improvement contractor, require a corrective action plan, or even terminate or refuse to renew the state's waiver. CMS is currently developing updated regulations regarding Section 1915(c) that could enable CMS to employ additional strategies to ensure state compliance with the requirements of a waiver, short of waiver termination or non-renewal, which can have pretty significant detrimental impact on individuals in the state.

The proposed regulations would also standardize and improve person-centered planning and establish standards regarding the characteristics of settings of care to better assure that individuals receive waiver services in settings that are home-like and provide a true alternative to institutional living.

Thank you for the opportunity to draw attention to CMS's efforts to provide Medicaid beneficiaries with quality services in their homes and communities, including in assisted living environments. CMS is committed to continuing our efforts to engage consumers, caregivers, providers, and states to better support the design and delivery of long-term care services that enable individuals with cognitive and physical impairments to have access to quality long-term care in their homes and communities.

[The prepared statement of Barbara Edwards appears in the Appendix on page 36.]

Senator NELSON. Thank you, Ms. Edwards.

Senator Corker, a statement?

Senator CORKER. I don't normally make statements, but I want to thank you for having the hearing. I know you've had some things, especially in your state, that raised alarms, and I appreciate you bringing it to our attention. Thank you.

Senator NELSON. Ms. Roherty.

STATEMENT OF MARTHA ROHERTY, M.P.P., EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF STATES UNITED FOR AGING AND DISABILITIES, WASHINGTON, DC

Ms. ROHERTY. Senator Nelson, Chairman Kohl, and Ranking Member Corker, on behalf of the National Association of States United for Aging and Disabilities, I would like to thank the Senate Committee on Aging for the opportunity to testify at today's hearing on assisted living facilities.

Assuring quality across the continuum of home and community-based services is a key priority for our association. NASUAD represents the nation's 56 state and territorial agencies on aging and disabilities which play a variety of roles with respect to assisted living. Some of our member agencies collaborate with their partners in the Medicaid agency to develop and operate Medicaid financed assisted living services, while others oversee assisted living operations in the context of the Medicaid quality monitoring strategies.

Additionally, many NASUAD members are responsible for the Adult Protective Services Program in their state, and most also administer the State Long-Term Care Ombudsman Program, as well as the information and referral agencies, including the Aging and Disability Resource Centers. Increasingly, individuals that need the long-term services and supports are choosing to live in residential settings such as assisted living facilities instead of nursing homes.

Accordingly, over the past several years, the number of beds in nursing homes has been on the decline while the number of beds in other residential settings has been steadily growing.

As this trend continues, so do the opportunities for us to work together to enhance the quality of care across the home and community-based continuum. As Barb mentioned, the only federal requirements for state oversight and monitoring of assisted living facilities exist in the context of the Section 1915(c) Medicaid waivers.

However, Medicaid licensed units comprise only a small portion of assisted living facilities. And there's no federal guidance outlining or enforcing a state's role in the oversight and monitoring of the private pay assisted living facilities which make up the majority of the marketplace.

In my formal written statement, I outline in more detail the core quality and oversight components that states deliver. But in my oral statement today, I'll focus on the five key recommendations supported by our members.

The first is building on the recommendations made by the Senate Aging Work Group that Senator Nelson talked about. NASUAD's first recommendation is for the development of a federal framework to help standardize the requirements for the Resident's Bill of Rights and a Disclosure Statement. Currently, about half of the states have requirements for residents' rights and virtually all have a disclosure statement, though the content varies considerably from state to state.

Federal guidance in this area along with suggested tools to help the states ensure compliance would promote national standards for assisted living residents while offering prospective assisted living residents and their families a consistent format for comparing assisted living options. NASUAD members also support an increased federal investment in options counseling, including counseling service delivered by the information and referral staff and the Aging and Disability Resource Centers.

Potential residents of assisted living, particularly those who could quickly exhaust their resources and turn to the Medicaid program, need objective third-party assistance with understanding their options, including what they can afford and for how long. Even with the federal support for this program that you're already giving us, states report that they do not have adequate funding to meet the demand for these services.

Our third recommendation is increasing the federal funding for state programs that provide resident advocacy services, including Adult Protective Services and the State Long-Term Care Ombudsman Program. Through a regular presence in assisted living facilities, ombudsmen are uniquely positioned to both monitor a facility's quality and address resident complaints. An increased federal investment would increase the program's ability to provide and ensure quality.

Given the responsive nature of adult protective workers who conduct investigations when they receive a formal complaint report, a federal funding stream dedicated to APS would similarly allow these workers to increase the program's existing capacity and better protect residents of assisted living facilities. Specifically, increased and dedicated funding would enable APS and ombudsmen

to leverage their authorized access which they currently have to assisted living facilities by allowing them to conduct more visits, both scheduled and unannounced, and these programs would be better able to supplement the work of the state survey and licensure agencies, which generally survey assisted living facilities once a year.

Fully funding the Elder Justice Act is the fourth NASUAD member recommendation. As the number of aging consumers grows, so does the need to protect the most vulnerable among us, in part, by improving the quality and accessibility of resources regarding long-term care, including assisted living.

The Elder Justice Act provides such consumer safeguards and protections, but does not provide funding to carry out the duties it was assigned. That is why, in addition to increasing the funding for the Ombudsman Program and dedicated federal dollars to the provision of Adult Protective Services, an adequate investment is also needed to implement the Elder Justice Act.

Finally, NASUAD members support a broad federal definition for assisted living that's based on the core principles of assisted living that were developed by the committee's work group in 2003. There is tremendous variation among the states in their assisted living definitions, and, therefore, the federal framework must be broad enough to account for the wide array of state models while still addressing the autonomy, choice, privacy, and dignity of all assisted living residents.

So thank you again, Senator Kohl, Senator Corker, and Senator Nelson, for your leadership on these important issues and for the invitation to testify here today. I welcome your questions and comments and look forward to continuing to work together to improve the quality of life for older adults and individuals with disabilities in whatever place they call home.

[The prepared statement of Martha Roherty appears in the Appendix on page 48.]

Senator NELSON. Thank you, Ms. Roherty.

Dr. Polivka.

STATEMENT OF LARRY POLIVKA, PH.D., SCHOLAR IN RESIDENCE, CLAUDE PEPPER FOUNDATION, FLORIDA STATE UNIVERSITY, TALLAHASSEE, FL

Dr. POLIVKA. Thank you, Senators.

I'm going to talk about three areas primarily regarding the assisted living situation in Florida. One is the origins of the governor's Assisted Living Work Group that I am the chairman of. Two is the mission of that work group. And three is current status and future plans.

The work group essentially came from concern about the reports in the Miami Herald that Senator Nelson referred to earlier in May and June of this year. Beyond that, however, there was also, I think, a general perception in the assisted living community, in the advocacy community, and among policy makers that we have not looked at assisted living in several years in Florida. And I imagine that's probably true in many states.

During that time, the program has virtually doubled in size. In terms of the population, it now has more—we now have more beds

in assisted living than in nursing homes, about 82,000. We have almost 3,000 facilities. And that's over about a 10 or 12-year period. We project at least that much growth in the next 10 years.

And so I think there was a general perception that it was time to take a systematic look at what we were doing in assisted living, both from a general policy perspective and from a regulatory perspective, to deal with some of the issues that have emerged over the last 10 years. And that, in some ways, culminated in the Miami Herald series.

And it's also true that we have had a huge growth in the Medicaid population in assisted living in Florida. Now, you mentioned, I think, Senator, there's about 130,000 people—maybe, Barbara, it's more than that at this point, because we've got somewhere in the neighborhood of 30,000 Medicaid supported people in assisted living in Florida. If you count the waivers, if you count the Assisted Services State Plan Program, it's getting over 30,000 in one state.

So, you know——

Senator NELSON. That's because there are a lot more assisted living in Florida, proportionately.

Dr. POLIVKA. And there's been this huge growth in 10 years. So with that as kind of the basis of concern and interest, the work group was formed by Governor Scott. It has 15 members. I am chair. And I think there's been some concern about representation, but we've had two meetings, and in my judgment, based on the discussion that has occurred within that work group and the interaction with the people providing public testimony, it's pretty representative, in my judgment. We'll see. I mean, we'll see what the outcome is over the next two weeks.

The mission was essentially to address any area that the work group decided was important, especially in response to some of the findings from the Miami Herald article related to the question of whether or not we have adequate rules and regs, sufficiency of enforcement, adequacy of qualifications and training among providers and administrators in assisted living. We're covering about 14 areas, and that's over a three-month period.

In terms of current status, as I mentioned, we've had two meetings. We've had many, many hours of public testimony that's been very useful in the forming. We have our last meeting Monday and Tuesday in Miami where we're going to consider a range of recommendations that we're going to report for the governor and the legislature by the end of November for consideration in the session that begins in January.

I have included, I think, in the materials that your staff has disseminated a number of recommendations that I'm making as a member of the work group—as just one member. We'll see what the other folks come up with. As a matter of fact, you can see them as of this morning. There are 14 or 15 pages of recommendations that are coming from work group members and from other organizations that are on the Medicaid web site in Florida since this morning, if you want to take a look at them.

I am also suggesting, though, that we have a Phase 2 of the work group. We have really had to scramble to cover areas that we thought were of most critical concern for the short term since August. There are a number of other issues that we have not had

enough time to really address thoroughly and effectively, one of which, in my judgment, is do we have the right regulatory scheme in place in Florida.

It has been my perception—and it's spelled out in an issue paper that I sent to the staff earlier today from 2006—that while we really need to detect and rid the system of chronically poor performers in assisted living, I think we also need to take a somewhat different approach when it comes to dealing with the regulation of most providers in assisted living. And sometimes that's referred to as a collaborative consultative approach. I refer to it as a collaborative consultative approach with a hammer, as far as bad performers are concerned.

And I would hope that we would have a chance in Phase 2 of the work group to look at this broader regulatory picture, because assisted living is an enormous resource. It's incredibly valuable, and, if anything, it's going to be more valuable 10 years from now than it is today. But we can't afford to have the whole thing undermined by 5 or 10 percent of the providers who are not performing and are not being regulated effectively.

Senator NELSON. And later on, when we get into questions—if you'll share some of your recommendations. Thank you.

Mr. NAVAS.

STATEMENT OF ALFREDO NAVAS, PRIVATE CITIZEN, CUTLER BAY, FL

Mr. NAVAS. Honorable Chairman and committee members, thank you for inviting me to share with you and the public the terrible, terrible accident due to negligence suffered by my mother. My name is Alfredo Navas. I am the youngest son of Aurora Navas. She was 85 years old when she accidentally died due to negligence at an assisted living facility in Miami, Florida.

My mom was always a hard-working lady. She was a strong lady. She was the pillar of our family. But she also had some weaknesses, which—as I speak to you, you'll realize why some of these things just don't add up. She was always—and I remember as a child how scared she was of water. She would panic when my kids would be in the pool playing. She would panic when we went to the beach.

And as she got older, later on in life, she was also very afraid of being in the dark. Even though she lived alone, she had night lights in every room so she was never in the dark.

After she became ill with this horrible disease of Alzheimer's, she was placed in an assisted living facility in Miami, Florida, where my sister lived. This made it convenient for her to visit her regularly. I lived in Tampa, so I had to commute and travel to see her as often as I could. And it was very difficult for my brother living in the panhandle.

But the first time, I remember, when I visited the facility, I walked in, and I wanted to make sure that my mother was in a good facility. I looked at the cleanliness. I looked up as I walked in. There was a camera there that would capture the entire movement of that home from that single position. Nobody could come out of the bedrooms, nobody could come in from the outside, nobody could move into the television room or the dining room or the kitch-

en or the living room or the back room without passing in front of that camera.

There was also a safety gate on the kitchen, where nobody could go in the kitchen other than the people working there. I also noticed the lake in the back. You could see the lake from inside the home, and I was concerned. I've heard of accidental drownings before, and I've read those in the newspapers, and I inquired about that. And I was told there's absolutely no way that they can get out there because the gates are locked.

I saw that the facility wasn't locked. Obviously, this was during the late afternoon hours, when I was able to visit, because that's the time when dinner was served and they were back from the activities that they did during the day. And I noticed the double door—the double knobs on the door. I inquired about that. Why is the facility open? Anybody can walk in.

I was told, "Well, those are safety features that we have on the doors. There's two knobs. One turns to the left and one turns to the right, and that's a safety, and we cannot lock the doors because of fire code regulations." I was also informed that they had alarms on the doors that they would set after a certain time of the night, that if anybody opened it, they would go off.

Well, unfortunately, about—the very early morning hours of January 27th, I received a very, very disturbing phone call from my sister. She was in a panic. She said that there was a terrible accident at the home and that mom had passed away.

I couldn't believe this. It can't be. So I rushed over there, and as I got there, just—reality sets in. Everything is taped off. We can't go in. The police are not telling us anything. So we had to wait. It was a dark, dreary, moist, and cold January morning, and I'll never forget it. I had a jacket on. We even had to sit in the cars with our heaters. It was so cold.

Well, after we saw the coroner's van come in and take my mother's body away, a police detective approached us and told us that—well, he walked us into the facility, into the entry way and told us what had happened, that mom had drowned in the lake, that she had walked out and she had drowned. And from his perspective, it was clear negligence, based on the fact that the alarm on the doors wasn't set, the gates weren't locked.

But there were a lot of questions raised after we received the reports. Now, we didn't get anything from any of the government agencies. We didn't get a report from the police. We didn't get an autopsy report. Nobody called us. So we named a lawyer, and through the lawyer, we managed to get copies of all the reports. And all that did was raise a million questions.

My mother's slipper was found in the kitchen on the floor. She went through those double door—with double handle doors. The alarm didn't go off. There was no rails on the two steps coming off the back of—the side of the home. My mother needed assistance to get into my car, in and out, but she managed to walk out in her nightgown on a very cold night, go at least 75 feet to the gate.

Her second slipper was found by the lake, and then they found her in 16 inches of water where she drowned. The autopsy reports—this is a drainage pond, as I call it, for the neighborhood, for the subdivision. And knowing how those drainage ponds are, as

soon as you walk in, the mud and the silt and all of that gets disturbed, much less falling in, drowning—if I was drowning, I'd be flailing, and that mud would be stirred up. My mother had clean water in her stomach but not in her lungs.

So it raised a lot of questions. We never received anything from the police, absolutely nothing. I know the—we find out that AHCA, which is the state agency that regulates the healthcare facilities in Florida, never even investigated.

So my questions are: How can a homicide detective conclude it was clear negligence and never pass it on to the state's attorney for further investigation? And where is AHCA? How is that connected to the legal side?

We did file a civil suit. We settled, but to my shock and amazement, Florida law requires a $25,000 policy for these regulators—these facility operators. It required a small air conditioning contractor to carry $250,000 liability insurance. And an air conditioning contractor does not deal with people's lives. These operators deal with people's lives. They've taken people's lives due to their negligence, yet we have a big disconnect, big disparity—and I apologize. I think I'm going over quite a bit.

But I'm real disappointed in AHCA. I am very, very grateful to the Miami Herald for bringing all these abuses, this neglect, to the forefront and making our communities aware and making you, our elected officials, aware that we have a great problem in Florida and most likely in every state where ALFs operate. I'm not saying that all are bad. But our senior community is growing by leaps and bounds as we, including myself, will be considered a senior person here in a few years, if not already.

Senator NELSON. Thank you, Mr. Navas.

Mr. NAVAS. Thank you.

[The prepared statement of Alfredo Navas appears in the Appendix on page 58.]

Senator NELSON. Thank you very much for your very heartfelt testimony.

Mr. Maag.

STATEMENT OF STEVE MAAG, J.D., DIRECTOR, RESIDENTIAL COMMUNITIES, LEADING AGE, WASHINGTON, DC

Mr. MAAG. Thank you, Chairman Kohl, Ranking Member Senator Corker, Senator Nelson, and Senator Manchin. I have submitted my written testimony. I'll briefly summarize that for the committee.

Leading Age, formerly AAHSA, represents almost 5,700 not-for-profit members who provide care and services to over 1 million seniors on a daily basis. Many of our members provide services which would fall under the broad category of assisted living. And I'm 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'm not personally familiar with the circumstances detailed in the Miami Herald, members of Leading Age 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 that the vast majority of assisted living providers work very hard to provide excellent care to

their residents they serve, and the circumstances cited in the articles are the exception.

I'll address two issues: quality of care and consumer disclosure. 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 quality care and services. Leading Age's own Quality First is an example. Quality First is a comprehensive plan many of our members use to maintain excellence in care and services. Other examples are the National Center for Assisted Living's Guiding Principles for Assisting Living and Quality Performance in Assisted Living and the Assisted Living Federation of America's Care Principles.

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 is the outgrowth of the efforts of this committee, as the senator mentioned, 10 years ago which resulted in the Assisted Living Work Group. CEAL was formed in 2004 and comprises 11 stakeholder organizations. We also have an advisory council of 27 additional stakeholders, 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 clearing house with almost 800 discreet items on almost every aspect of assisted living; developing the Excellence in Assisted Living Awards to highlight and disseminate best practices in five different practice areas; publish—and publishing last summer "The Person Centered Care in Assisted Living: An Information Guide."

Lastly, I should also point out that there are resources directed at consumers of assisted living services, the residents and their families. One such is the Consumer Consortium on Assisted Living. Their web site has a huge amount of information, all geared to the consumer. I would suggest the use of these resources may have prevented the quality of care issues raised by the Miami Herald.

While I recognize some officials may look to more regulation to address the bad acts of providers, I urge the committee and others not to look for more regulation. 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 that they need to raise their level of care to that of the rest of the assisted living providers.

I'd like to note that Wisconsin, Senator Kohl, has done an excellent job in advancing that perspective.

Now, I'm not naive enough and I've got enough gray hair to understand that there—and not to suggest that there isn't a major role for regulatory oversight in assisted living. It already occurs in all 50 states, and Leading Age and the other provider associations strongly support regulatory frameworks.

I recognize there are occasional quality of care concerns in assisted living communities in all parts of the country. However, my experience and the experience of many in the long-term care services and support sector have not seen additional regulation as the best way to improve quality of care.

Turning to consumer awareness and disclosure, there's clearly a need for increased resources for consumers to understand what assisted living is and is not, as well as an understanding of which assisted living provider may be right for them or their loved ones. They often lump assisted living in with nursing homes. They are distinctly different, as we all know.

States are taking significant steps to address consumer issues. Thirty-seven states have some form of disclosure statement or requirement for the assisted living provider to make information available to prospective residents and their families. Forty-nine states have regulatory requirements for residency agreements mandating that they contain certain consumer protections. Several states have web-based information. There's many organizations I've previously mentioned, such as CCAL, which have a wealth of information, and there's also commercial sources, such as Snap for Seniors and New Life Styles.

This is one area where we think that providers, state regulators, and agencies like the U.S. Administration on Aging and the Office of Long-Term Care Ombudsman Program could work together to find ways to increase consumer awareness. Better educated consumers are in everybody's best interest and is something that the provider community strongly supports.

Lastly, an example of this kind of effort is the Assisted Living Disclosure Collaborative that the Agency for Healthcare Research and Quality launched three 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 community.

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. This disclosure tool has been developed and will be undergoing field testing in eight states and in over 100 communities after OMB clearance.

Thank you for this opportunity to testify on these important issues.

[The prepared statement of Steve Maag appears in the Appendix on page 62.]

Senator NELSON. Thank you, Mr. Maag.

Mr. Jenkens.

STATEMENT OF ROBERT JENKENS, DIRECTOR, GREEN HOUSE PROJECT, NCB CAPITAL IMPACT, ARLINGTON, VA

Mr. JENKENS. Thank you, Senator Nelson, Chairman Kohl, Ranking Member Corker, and other members of the committee. As Senator Nelson mentioned, I am the Director of the Green House Project, a partnership between NCB Capital Impact, the Robert Wood Johnson Foundation, Dr. Bill Thomas, and the pioneering states and providers who have joined with us.

The Green House Project assists organizations to implement a radically different approach to long-term care, one that truly operationalizes the founding values of assisted living, autonomy, dignity, and privacy. Prior to the Green House Project, I directed the Coming Home Program. The Coming Home Program worked with nine state partners to implement and refine Medicaid waiver regulatory and housing finance programs for assisted living projects serving Medicaid eligible individuals.

Through the Coming Home Program and the Green House Project, I have learned just how good assisted living can be. So how do we square the successes I have seen created through committed public-private partnerships with the horrific stories bravely brought to life by the Miami Herald? How can we think about these opposites and use the successes to inform us on how to prevent abuses without stifling innovation?

Four observations from my experience: First, as the Miami Herald found, the incidents of significant abuse and neglect are limited to a small fraction of the providers operating in Florida. This is good, because it means that most organizations can be part of the solution.

Second, the existing state complaint and review process appears not to have been followed or enforced. The Herald coverage suggests that if the complaints had been pursued, some of the worst outcomes may have been avoided. While the lack of enforcement is troubling, it means the elements of a solution may already be in place.

Third, this regulatory failure and similar failures in other states suggest that financial and political pressures sometimes prevent the implementation of sound state quality assurance systems. This is an area where we can foster significant improvement.

And, fourth, it's important to note that assisted living quality is not a federal or state versus provider problem. The providers and trade associations I work with daily are united in their calls for abuse and neglect to be punished swiftly and fully. This is motivated by their personal missions and business interests. This motivation is important because it means that their interests are largely aligned with consumers, regulators, and providers.

So what should be done? Do we need more state action? Is there a different federal role needed? I think the answer to each of these questions is yes. I believe strongly that the goals of quality assurance, innovation, and cost effectiveness are not mutually exclusive. In fact, I think they are necessary complements and that we already have the overall state and federal regulatory framework in place that we need. We simply need to refine and bolster the framework to allow it to fulfill its intended purpose.

My first recommendation is to refine the balance between state flexibility and accountability. Currently, the federal Medicaid waiver approval process allows states to propose quality standards and systems. While this is the right place to start, clear federal expectations should form the foundation of any state proposal. It's not enough to defer to a state's process entirely where federal funds are involved.

To create appropriate guidelines, standards that make sense to advocates, consumers, and providers, the Centers for Medicare and Medicaid Services, CMS, should be asked to develop these guidelines through an inclusive stakeholder initiative. This stakeholder initiative should be modeled on the successful Assisted Living Work Group formed in response to this committee's challenge in 2001, or the more recent 2011 efforts of the successor organization, the Center for Excellence in Assisted Living.

Building on the process and recommendations from both of these groups and with the assistance of a team of CMS advisors, strong guidelines could be developed over the next six months. At the direction of Congress, these guidelines could form the firm basis on which CMS evaluates, renews, and approves states' quality assurance proposals.

My second recommendation is targeted at accountability. The severity and duration of the quality crisis uncovered by the Herald provides evidence that CMS's oversight role in the waiver program is not yet sufficient. We know this is not because CMS staff do not care enough, but rather because they lack the tools and resources to effectively monitor and enforce waiver performance.

CMS does not have the necessary staff or structure to verify state quality assurance for home and community-based waivers. We need something more than we have. The work group brought together to develop guidelines could also make recommendations on a more effective federal monitoring and enforcement role, including intermediate sanctions. Congress could then elevate these recommendations—evaluate these recommendations and direct CMS to implement selected enhancements and provide additional funding as required to assure that beneficiaries of this essential industry do not suffer due to lax oversight.

Thank you again for this opportunity to testify today. I look forward to your questions.

[The prepared statement of Robert Jenkens appears in the Appendix on page 70.]

Senator NELSON. Thank you, Mr. Jenkens.

Mr. Chairman, since you have another commitment, we want to thank you for the privilege of holding this hearing. And we want to give special credit to the Miami Herald for the extensive three-part series that they did on this subject.

Senator Corker.

Senator CORKER. Thank you, Mr. Chairman, Acting Chairman. I appreciate you bringing this to our attention and all of you for your contributions today.

Mr. Navas, in particular, I thank you for coming and sharing your personal story. And, you know, it always makes a major difference in any of these hearings or in our offices when someone like you has been affected this way. So I thank you for having the cour-

age to be here and for telling your story, and for all of you for your contributions.

And it's really interesting—Mr. Jenkens' testimony here at the end, I guess, brings me to my first question, and I'll be brief with all of these. I used to be a commissioner of finance for the state of Tennessee and was constantly dealing with the waiver processes. And, you know, we wanted to—we were actually hugely progressive in doing a lot of things as it relates to covering people, but constantly having difficulties with CMS and the waiver process. And I understand, as he mentioned, that there's a lot of staffing issues and that kind of thing.

Tennessee has sent you a letter recently, on August the 25th, requesting guidance on a maintenance of effort requirement in PPACA. And it's really holding them up from being able to move ahead for their long-term care efforts under something called TennCare Choices. Again, I think Tennessee has been a leader in many of these things.

And I just was hoping you might let me know when you expect they might have a response, Ms. Edwards—really, right along the same lines of Mr. Jenkens' testimony.

Ms. EDWARDS. Mr. Corker, I appreciate your question. Tennessee, in fact, is considered a national leader, particularly in terms of thinking about ways to make community-based services a first choice for individuals who need long-term services and supports. We've really admired the work they've done and the way they've done it in collaboration with their advocacy and stakeholder communities in the state. We hold them up as a model frequently.

We are looking carefully at Tennessee's request. We do understand the urgency for them. We have a team of folks who are looking very hard, and the challenge is, of course, that the Affordable Care Act does have pretty specific provisions with regard to maintenance of effort. And because eligibility for long-term services is frequently intertwined with eligibility for Medicaid itself, there are issues that get raised in the proposals that Tennessee has put forward.

I can't give you a specific date, but I will tell you it is a very high priority for us. We're working on it as we speak. And my boss, Cindy Mann, and others throughout the agency are very focused on this issue. So I think Tennessee will have an answer soon.

Senator CORKER. Thank you. And I appreciate your focus on that, which brings me to Mr. Polivka.

There's been a movement to look at some greater regulation of assisted living within states. And yet at the same time, we constantly have this rub that exists. I mean, the federal government has regulations. It ends up, especially with good actors in states, in many ways holding them back from doing things that are better for their population they're trying to serve. And so I'm very resistant to that type of thing as a result.

And back to the state of Florida, we heard the incident—I mean, what kind of state regulatory process does exist in the state of Florida? How focused is it? How powerful is it? How do you feel about the situation right now as it relates to assisted living in Florida?

Dr. POLIVKA. I think that part of the problem was the one I mentioned earlier, that is, we—and that's everybody in the state, policy

makers, providers, everybody, the media—have not paid as much attention to assisted living as we should have over the past several years. As the program grew, as it became much more common for people with Medicaid funding to be placed in assisted living, we didn't keep up with the process.

The program grew. Some of the issues became more complicated, and there was not an adequate kind of policy regulatory response to those developments over a period of five to 10 years. I think that there has been a major upgrade in regulatory activity in AHCA, the Agency for Health Care Administration, which is the Medicaid program for Florida, over the last six months and especially since May and the Miami Herald series.

I think it also comes in part with the new administration. Secretary—the new secretary has—began to prioritize enhanced regulation, or more effective regulation——

Senator CORKER. Just for—they only give me a limited amount of time, and I very much——

Dr. POLIVKA. Sure.

Senator CORKER. I sort of got the history of it, but, apparently, there's not much of a regulatory process is what you're, I think, getting at.

Dr. POLIVKA. No. I would say that it was not sufficient. And I would say that the effort has been accelerated over the past three months, four months, and that with the work group, it will be accelerated further in several significant ways.

Senator CORKER. And, again, not being critical in any way—I know you all are new to the job. Is Governor Scott asking for federal regulation over assisted living in the state of Florida?

Dr. POLIVKA. Not that I'm aware of.

Senator CORKER. And I would think there would be a lot of states that would not want to see that happen. I know there is, again, through the application process, some things that CMS does in that regard. On the other hand, in Florida, it seems that a large part of your assisted living—or a portion of your assisted living population is actually younger people with mental illness, which is kind of unusual. Do you want to speak to that?

Dr. POLIVKA. Yes. That was one of the issues I thought we might get to later in more detail. One of the major issues in the Miami Herald series related to what's called limited mental health license facilities. And somewhere in the neighborhood of maybe 40 percent of the people in assisted living who are publicly supported are people who have mental health issues. And those facilities seem to be at greater risk of problems of the kind that were described in the Miami Herald than ALFs that do not have people who have mental health problems and who have a limited mental health license.

So my impression is that in the meeting Monday and Tuesday of next week, a good portion of our time and the recommendations will focus on those mental health residents and mental health license facilities. It's become one of the major housing options and has been for over 20 years for publicly supported people with mental health problems in Florida. I'm not sure how this is handled in other states, but you're right. It's a big issue in Florida and has been for a long time.

Senator CORKER. Mr. Chairman, thank you. Just in closing, I know Governor Scott, and he obviously was actually involved in Tennessee and was a provider to much of the Medicaid population there through the company that he was CEO of. But what happens, I guess, in states, if states don't do the things themselves that ought to be done—and it sounds like in the state of Florida—and, again, I know you all are new to the process and I'm not in any way casting blame on you.

The state of Florida, it sounds like, has a lot of work to do. And when there ends up being especially such a high concentration of people, as the senator has mentioned, in assisted living, and then bad things happen, there happens to be sort of a whiplash effect in Washington, and Washington tends to want to then put in place federal regulations that sort of end up being one size fits all and can actually, in some cases, hurt the system, not help it.

So I would hope that you guys would recognize that and would not cause actions in Florida to end up having negative activity, from my perspective, occur across the country.

Dr. POLIVKA. Senator, we're working on that. We're doing our best. I'm optimistic about some of the changes, both short-term and longer-term. But we'll see what actually happens. And let me say that the recommendations that Robert made and that Barbara was talking about in terms of the CMS role, I think have lots of merit in terms of oversight and waiver approval and critique. There's real potential there.

Senator CORKER. Thank you. Thank you very much.

Senator NELSON. I'm going to turn to Senator Manchin, former governor, who had to do this from his perspective as the chief executive. But we're picking up a thread here that these ALFs are really starting to take the place of nursing homes, it sounds like, in some of these, and that's not supposed to be the theory. The theory is supposed to be that there's independence of living, and that they just get assistance. We'll come back to that.

Senator.

Senator MANCHIN. Thank you, Mr. Chairman. And to follow up on what Senator Corker had been talking about in Tennessee—and being a former governor, we worked on all of these things. You're right. It's mostly up to the states or states' rights to take this responsibility, and it should be a moral responsibility.

So West Virginia, I think, if I'm not mistaken, is the second largest concentration of aged people. I think Florida is first and we're second. And with that being said, we know that we have our challenges also. But I would just ask—and, Ms. Edwards, if you would—to a couple of these things here.

Senator Corker makes a good point, and we're afraid, you know—we don't do anything "a little bit" up here. I've only been—I'm the newest guy on the block—one year. I can tell you when they want to make a change, it's a big change, and there's concern. So what happens sometimes—we might not do anything for the sake of trying to do too much.

Now, with that being said, there's got to be a happy medium. But I can't understand why we can't at least have reporting. Is there registration? Is there licensing in Florida? I'm not sure if you all—since there's no Medicaid or Medicare money, do you have ombuds-

men that go into these places that look at all these things? And I'm sure that you have a very active and aggressive trial lawyers association that watches you very close or watches this organization or these homes very close. Maybe that's the check and balance. I'm not sure.

But we, basically, put them in categories, six or fewer, depending on the size of the homes that we had. As far as those growing more, we've had a moratorium on nursing homes for quite some time because the expense—and if you know, the expensive nursing home. And then when you look in most states, 80 percent of the occupants is paid through Medicaid.

So, you know, people have learned how to divert their assets and their income, and they become wards of the state. That's why you haven't seen nursing homes flourishing and growing and expanding. So this is an alternative. But something's going to have to be done. And maybe from your standpoint, what you think we could—in a reasonable manner to get a better handle of what's happening right now.

Ms. EDWARDS. Senator, I want to start by being clear that CMS does not have a position seeking additional federal oversight or additional licensure requirements at this point. What we are committed to doing is using the tools that we do have, as was mentioned earlier by another panelist, to do the best that we can to help states assure that people have good systems and people are being protected in terms of their health and their wellbeing.

What we do in our waiver programs, which is where most of these services that Medicaid funds are funded through, is we ask states as a part of the application to tell us what the services are going to be—lots of flexibility in waivers, as you know—what the services are going to be, what the population that's targeted for those waiver services may be, where individuals can be and receive those services, what standards the state has established for those settings of care, and who the providers can be of those services and what standards the state has set for those providers.

What we even require states to do is to report to us on how they are overseeing their own system of oversight and regulation. We ask states to do sampling of members who are receiving services; to report on whether or not people are getting level of care determinations; whether or not they have a plan of care; whether or not that plan of care is being followed; whether or not there are instances of abuse and neglect and, if so, how has the state responded to that. So we are——

Senator MANCHIN. What are you able to do as far as——

Ms. EDWARDS [continuing]. Asking for reports.

Senator MANCHIN. But what is the hammer? You've got the carrot. What's the—you don't have a carrot or a hammer.

Ms. EDWARDS. You've put your finger on it. In fact, the only real hammer that Medicaid has is to deny the waiver. So we can—we could—quit funding the services. We have found that to be—I mean, most states want to do a good job. So states are usually willing to work with us, develop plans of correction if they find problems in their system or if we find them.

But we really don't have a lot of interim steps. One of the things that we have proposed in a Notice of Proposed Rulemaking that

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went out in April was to create some additional intermediate steps that we could take if, in fact, states are not coming to the table in good intention to make corrections. For example, withholding some funds for the waiver program, all of them, that sort of thing ——

Senator MANCHIN. Let me ask this question, because we're running out of time. I'm so sorry, but we're going to be running out of time. Like in our state, if we know that someone is Medicaid eligible, and they're not really nursing home needed—they don't have the need of a nursing home, skilled—but they need that assisted living, we will offset the difference in our state, because it's much more, I think, the right thing to do, and it's much more cost effective for us to do that. I don't know if other states are doing that or they'd like to do that, to pay the difference and help Medicaid.

Ms. EDWARDS. Very popular—some states will pay the difference. You're talking about room and board, I think.

Senator MANCHIN. Right.

Ms. EDWARDS. You're helping to subsidize the cost of room and board.

Senator MANCHIN. Yes.

Ms. EDWARDS. It varies widely across the state whether or not there is any subsidy available.

Senator MANCHIN. Let me just say this. I just want to applaud Senator Nelson, because I know with his state and the aged population—and he's concerned about Florida. I can tell you that. We talk about it every day—but bringing this to our attention, because we all face it, and we're going to be facing it in greater numbers than we've ever faced it before. I think there's thousands of people going into the need of care on a daily basis. We're all growing a little older every day. That's the good part. The next part is we need someone to help us.

So with that, if we could find something—and, Senator, I applaud—and I'd work with you—that doesn't overreach, but basically gives a guideline of just moral care, and it gives you all the ability to go in.

If you send an ombudsman in, what do they report back to, and what can they do, other than saying, "We think there's a problem here." And if I can—if I may—are you able to pull a license from an assisted—in Florida right now, if you find that the person is not—I know with the sprinkling systems and if they're able to have access and things of that sort—but what allows you—I mean, could you toughen that up a little bit there, to pull a license if needed?

Dr. POLIVKA. Yes, sir. That is an issue, in fact, that we'll be discussing Monday and Tuesday. It's an issue related to how much discretion should the regulator have. There needs to be some, but it's a balancing act. And I think that there will probably be a recommendation or two that may be adopted by the work group related to reducing discretion on the part of regulators, especially in cases of egregious injury or death in a facility that would lead to quick revocation—if not immediate, then within a time frame with some appeal, but it would occur fast.

That has not been the case so far. This may be something that we need at this point.

Senator MANCHIN. Thank you, Mr. Chairman.

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Senator NELSON. Well, the states ought to have the regulatory authority to enact whatever action under state law that they deem appropriate to correct a particular activity. Licenses is certainly one. But there's a multiplicity of other things through the state agencies that oversee these institutions.

Now, what is so revealing in the Miami Herald article is example after example of egregious conduct on the part of the facilities, and some of them didn't even get a slap on the wrist. And from the federal standpoint, we require an ombudsman, but the ombudsman is under, basically, the authority of the governor. And so even though there is a watchdog that the federal government requires, what that watchdog does is entirely up to the state.

So we need to get this out in the open. And I'm going to get to the disclosure in a minute, Mr. Navas. But let me first turn to Senator Whitehouse.

Senator WHITEHOUSE. Thank you, Chairman. I appreciate very much that you are holding this hearing.

It's a pleasure to be sitting next to Senator Nelson. We sat next to each other for four years on the Intelligence Committee, and I had the chance there to see how extremely tenacious the senator could be when the interests of a Florida constituent were at stake.

There was a family that had—a Florida family that had lost an individual, and some of our intelligence services were facilitating the search for and efforts to rescue that individual. And watching Senator Nelson at work, pounding on the Intelligence Committee to make sure they left no stone unturned and did every conceivable thing they could to help this family, was a good lesson for a new senator on how hard to fight for constituents.

I know this is part of that tradition. I appreciate it, Bill.

Ms. Edwards, there is not much regulatory authority here for the federal government. There are under Section 1915(c), I believe, something called quality improvement strategies. I believe that's a feature of the Affordable Care Act, if I'm not mistaken. How useful is that tool at addressing a problem like this? Or do you come back to what we were talking about just a moment ago, which is that the only hammer is just statewide, the waiver itself, and so it's one that you really can't use with any precision?

Ms. EDWARDS. Thank you, Senator. The quality improvement strategy that's a part of the 1915(c) program, as you noted, is something we actually developed collaboratively with states and began using back in 2002. There is a new requirement for Medicaid to pursue quality improvement strategies more broadly that was a feature of the Affordable Care Act, and the center will be doing more work in that arena over the coming years.

We find the use of a quality improvement strategy is really about paying attention to the health of the system that's in place. We ask states to identify how they are making—how they are going to assure that people have health and—or that their health and welfare is protected, that their level of care is determined, that the providers meet the qualifications the state has established for them, and so forth.

States do sampling. States report to us. And from that report, we work with the state at renewal to determine whether or not the state has met its obligations or not to have the waiver renewed.

Senator WHITEHOUSE. That's operating at a level of——

Ms. EDWARDS. It is not useful to deal with a specific assisted living facility that might not be meeting its state licensure requirements.

Senator WHITEHOUSE. It's system-wide rather than——

Ms. EDWARDS. It's a system-wide issue. That's right, sir.

Senator WHITEHOUSE [continuing]. Institution by institution.

Ms. EDWARDS. Right.

Senator WHITEHOUSE. Well, the federal government probably ends up picking up a measure of cost when there are problems like this, not in every case, of course, but where—because somebody has to be upgraded into a nursing home environment that CMS has to pay for, or for whatever reasons—we could end up at the federal level holding at least a piece of the bag from this problem. So I suspect it's something you look at fairly regularly.

In terms of which state has what best practices for trying to encourage the best quality of care in assisted living facilities, are there any standouts that you would flag for us?

Ms. EDWARDS. I think I am reluctant, Mr. Whitehouse, to actually recommend any states to you, because Medicaid's involvement with assisted living is really so narrowly focused that I think we really are not the experts on that. We certainly have—I think some states are doing a good job in their approach to their quality improvement strategy. We're actually committed right now to working with the states to actually do quality improvement on our quality improvement process.

So we're examining that process right now and hope to work with states to better focus it and make it more effective. But I do think that—you know, I'd be happy to work with my staff and see if we could identify some states for the committee that we think are doing a particularly good job with quality improvement. We'd be happy to share that with you.

Senator WHITEHOUSE. That would be helpful. I'd appreciate it.

Senator WHITEHOUSE. Ms. Roherty, I'm from Rhode Island. In Rhode Island, our state regulation for these assisted living facilities has a section called "Rights of Residents." And it lays out consumer rights for assisted living residents, including the right to be free from verbal, physical, and mental abuse; to have medical information protected; to have visitors at their discretion; and to have access to the state ombudsperson, among others.

And you advocated here for a federal assisted living Bill of Rights. Would that—how would that relate to what we have in Rhode Island? Would you consider that to be the type of bill you are talking about?

Ms. ROHERTY. As I said, about half the states have a similar thing to what Rhode Island has, and it would incorporate what Rhode Island has in place. I think that would be very helpful.

Senator WHITEHOUSE. I don't know if anybody knows the answer to this question. Is it customary in contracts for assisted living services for the providers to put into the contract requirements that people go to arbitration and so forth rather than—do you have to give up your rights to a jury as part of this ordinarily?

We've had some hearings about how—you know, you try to get your cell phone contract, and it's take it or leave it, and you don't

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have any choice. And buried in the fine print is, "Oh, and by the way, despite the fact that you're an American, despite the fact that the jury is in the Constitution and Bill of Rights not once but three times, congratulations, you just gave it up"—ditto with credit card agreements and various other consumer contracts. And I'm wondering if this falls into that same pitfall.

Mr. MAAG. Senator Whitehouse——

Senator WHITEHOUSE. Mr. Maag.

Mr. MAAG [continuing]. I was an attorney representing providers in a prior life and had considerable experience with this. My experience with arbitration agreements is that it's been an evolving practice. And I think most provider associations and Leading Age certainly provides that arbitration is an acceptable option for a contract provision if all parties agree to it, and that there is full disclosure and they understand what the ramifications are.

Arbitration, historically, as a preferred public policy is also something that can be the benefit to both consumers and providers in quicker resolution to issues, more certainty to issues, a much less expensive process. But having said that, we don't support a situation where the arbitration is a mandatory provision of the contract; it's something that's forced on consumers. We think that that should be a separate part of the admission agreement. And if the consumer decides that they don't feel comfortable signing an arbitration agreement, they shouldn't be required to and it shouldn't be a condition of the contract.

Senator WHITEHOUSE. Yes, that seems like a reasonable way to proceed. Clearly, there are benefits to arbitration, but it's the sort of thing that should only be undertaken knowingly, particularly given the history we've had in this country where the largest private arbitration firm proved to be a racket run specifically to defeat consumers and had to be shut down by the state attorneys general for that reason. So it's something to be watchful of, and I appreciate your attention to it.

Thanks very much, Chairman. Thank you for your energy in this area.

Senator NELSON. Lest, say, for Mr. Navas' testimony about the tragedy involving his mother, lest this hearing be too sanitized, I want to directly quote from this Miami Herald article so we know—and it's part of the record. And, of course, the Miami Herald article will be entered in the record as part of the record. But I just want everybody to hear this.

"One of them in the Panhandle was like a prison camp—powerful tranquilizers, beating them. The conditions in the facility were not fit for a dog. Regulators had shut it down but then allowed it to keep open for five years with the continuous abuses.

"One woman was thrown to the ground, forced to sleep on the box springs because she had urinated on her covers. A 71-year-old woman wandered and drowned in a nearby pond. A 75-year-old Alzheimer's patient was torn apart by alligators after he wandered from his assisted living facility.

"A 74-year-old woman was bound for more than six hours and the restraints pulled so tightly they ripped into her skin and killed her. In Hialeah, a 71-year-old man with a mental illness died from burns after he was left in a bath tub filled with scalding water. The

Agency for Health Care Administration had failed to monitor the shoddy operators.

"A resident was eating from a filthy food bin. Four inches of dirt was on the floor of a dorm room, and six residents were drugged on tranquilizers without doctor's orders. And after this five years, one of those—he was given a year to find a buyer.

"Another one cramped in a dirty bedroom. They didn't give him food. They didn't give him water. They never gave him the medicine that would have saved his life. Another one vomiting and defecating in his bed—refusing to clean him because the stench was too strong. Despite the pleas from the other residents that he desperately needed help, caretakers never called the paramedics to try to save his life.

"At one called Hillandale, punishment was swift and painful—violent take-downs, powerful tranquilizers that made them stumble and drool. And the staffers would scream and tackle them when they misbehaved. The worst was the closet, a cramped room at the end of the hallway where the residents who were deemed unruly were locked sometimes for hours.

"And at one point, when the staff protested the removal of a 47-year-old man, the residents shouted and blocked the path for him to leave. And it took them calling the sheriff's office to clear a path and break up the crowd in order to allow him to leave the facility."

Now, I mean, it keeps going on and on. And, of course, we can point out to the fact that this is just a minor, minor percentage. But this is America in the year 2011, and these kinds of things shouldn't be happening.

Mr. Navas, what kind of information would have helped your family pick a good assisted living facility?

Mr. NAVAS. Senator Nelson, I'm not sure what kind of information would have really assisted us. My sister is the one that went through the selection process. I believe that a friend of hers that works for the Department of Children and Family had recommended this facility. But as we looked into this matter of these facility issues deeper, we found that this particular operator has nine licenses under—each license is under a different corporation.

They also move all their personal assets to trusts, and lawyers are—I heard a gentleman to my left here mention that. And it was very difficult for us to find any lawyer to take it, because once there's a trust in place, and the law requires a minimum policy of—insurance policy, there's no money for the lawyers.

Senator NELSON. So there were no assets to go after. There was only a $35,000 insurance policy?

Mr. NAVAS. Twenty-five thousand——

Senator NELSON. Twenty-five.

Mr. NAVAS [continuing]. Is the minimum for Florida for these operators.

Senator NELSON. And you did not know that as a piece of information——

Mr. NAVAS. No, I——

Senator NELSON [continuing]. Having put your mother there.

Mr. NAVAS. No, and we weren't looking at those things because——

Senator NELSON. Sure. Sure.

Mr. NAVAS [continuing]. We weren't expecting anything to happen. But the worst that I see happening—and I apologize because I see it here also. I'm a former administrator in a private corporation, and our solution is funding, funding, and funding. Well, some of them—many of the incidents that you mentioned, Senator, in the Miami Herald were five, six, seven years ago when funding was at its heydays in every state. Our economy has only gone downhill here in the last few years. So what happened there?

Senator NELSON. When you were making a decision to go in that particular home, you said that you went and visited, and it looked fairly good. Would you have—had you wanted to inquire as to the quality of that place, would you have known at the time how to go about getting the information to determine the quality?

Mr. NAVAS. Not at all. Not at all. I know my sister signed a contract with the operator. But in there, I don't believe there's anywhere—or any information to say you can research this operator or this licensing through this agency. And in the case of Florida, it's AHCA, or the Agency for Health Care Administration. And——

Senator NELSON. In any of your experiences, have you ever seen this taken to a prosecution? Have the state attorneys ever gotten involved in any of the states that you all have an experience with?

Mr. MAAG. Senator, there have been a few cases where attorneys—it's more likely a local prosecuting attorney has taken an action like that. I'm originally from the state of Washington, and I do know of a few examples in that state. The difficulty, obviously, is the burden of proof and the evidentiary standards for a criminal prosecution. But it has become more common, and many more state prosecuting attorneys' offices and local district offices are looking at elder abuse situations, including these kind of circumstances, and becoming much more proactive across the country.

Senator NELSON. Ms. Edwards, could you give us some more details on the health and welfare assurances that states provide to CMS?

Ms. EDWARDS. Senator, we ask for states to tell us what their standards are in their state; to identify who the providers are for the services that they're identifying; what the licensure standards are for those providers or training or credentialing, depending upon what the service is—they're not all facilities—telling us where people can receive services and if they have standards for those settings of care. Whether it's an assisted living facility, a group home—it might be in a school, it might be in the work place—are there, in fact, standards and what do they look like.

We ask states to assure that people have a person centered plan of care that works with that individual—and the individual chooses to say what they need and how they would prefer to get those services—and deals with mitigating risk for individuals. We ask that individuals have a proper assessment of their need, and we ask states to assure us that they have oversight of the standards that they have established.

Who is the licensing agency? What's their responsibility? How often are reports made? We ask for sampling of participants to assure that the assurances the states have given us are, in fact, happening. And we work with states if we find shortfalls.

States are expected, in fact, to identify for themselves where they have shortfalls and to put corrective action in place to prevent abuse and to improve their own systems. That's the expectation. And, obviously, because states have a lot of flexibility in what their standards are, we see variation across the states.

Senator NELSON. You list a litany of questions that you ask. And with regard to action, you mentioned one thing. You said, "We work with the states." Describe that. And do you have any other things that you can do if a state isn't living up to its assurances?

Ms. EDWARDS. Senator, we have—we require from states corrective action plans if there is a shortfall that is identified, and we offer technical assistance to states. We have a national contractor that works with states on their quality improvement programs, and they will literally go onsite to states to help them in improving their programs.

We offer technical assistance at the staff level. As I mentioned earlier to Mr. Manchin, we don't have a lot of sanctions available, interim sanctions. Ultimately, what we can do is refuse the waiver. We can terminate or non-renew a waiver and stop all the funding that's flowing to the individuals that are being supported. It's sort of a nuclear option.

And so we would like to have additional sanctions when states are not aggressively pursuing corrective action. We don't think it would be used often, but we would like to have them when we need them. We have proposed in a regulatory—in an NPRM that we have the ability to, for example, put a moratorium on more people moving into a waiver program if a state's quality assurance is not sufficient and even to withhold funding for administrative—or a portion of the funding that goes to the state, rather than all or nothing, as a way of getting——

Senator NELSON. You don't have that option?

Ms. EDWARDS. We do not have those options.

Senator NELSON. It's either all or nothing.

Ms. EDWARDS. Yes, sir.

Senator NELSON. And it's all or nothing, not with regard to a specific ALF, but with regard to the entire funding going to that state.

Ms. EDWARDS. All of the individuals receiving waiver services would lose that waiver support if we deny or terminated the waiver. So it is a very difficult tool to use.

Senator NELSON. Well, you do have the bully pulpit.

Ms. EDWARDS. Yes, sir.

Senator NELSON. A bully pulpit that was filled by the Miami Herald, I might say.

Ms. EDWARDS. Yes.

Senator NELSON. How do you use the bully pulpit?

Ms. EDWARDS. We are probably more subtle than the Miami Herald in our interventions, and——

Senator NELSON. Well, obviously.

Ms. EDWARDS [continuing]. There's a role for both of those things. I will say that when we received a copy of the Miami Herald article—which was, by the way, forwarded to us by the Office of Civil Rights at Health and Human Services—we immediately contacted the state. Our regional office and our central office team—we have a protocol for responding to those kinds of situa-

tions, whether they come in the paper or they come from a consumer or come from our inspectors.

And we talked with high-level state officials within a couple of days of those articles to ask for more detail about what the state was doing to respond to those situations, how the state had handled those situations at the time, and within a couple of days had sent a written response to the state for detail. And the state did report back to us on their activities to respond.

We actually view this as still an open issue with the state and are continuing to gather information. We believe the state has taken responsive action to investigate and to, in fact, do the kind of systemic review that's been described here. That's exactly what we want to see. And so we are continuing to monitor what the state is doing and continuing to offer assistance, but also continuing to encourage the state to be assertive and aggressive in its efforts to assure that its systems are adequate.

Senator NELSON. Isn't this the purpose of an ombudsman? We require an ombudsman. I haven't heard anywhere in this that the ombudsman says there's something rotten in Denmark and start pointing the finger. What's their role?

Ms. EDWARDS. Senator, I hate to say this, but the ombudsman is not a CMS responsibility, and so I really don't feel like I'm in the position to speak——

Senator NELSON. It's a state responsibility.

Ms. EDWARDS. Well, there is an Administration on Aging program for the ombudsman. Martha might actually be able to say more about it than I can.

Senator NELSON. Ms. Roherty.

Ms. ROHERTY. I can address it. Our state agencies on aging have the ombudsman program underneath them, although they are supposed to act outside of the agency because they do represent the consumer voice. And they are supposed to draw attention to it, and they frequently do at the ire of the governor. I understand they do report to the governors.

But I can tell you from our experience, I've had many ombudsmen calling the media and reporting on abuses, and then the governor's office calls our—my commissioners and says, "Why did you allow that to happen?" That's their job. Their job is to look for these facilities, and that's——

Senator NELSON. Did Florida have one when all of these abuses that were chronicled by the Herald——

Ms. ROHERTY. Yes.

Senator NELSON [continuing]. Happened?

Ms. ROHERTY. Yes. Every state has a state ombudsman, and there is a federal funding stream from the administration down to the state. The problem——

Senator NELSON. Well, maybe we should have had that person here answering the questions. Why didn't they blow the whistle? Or why didn't they know? Is that the role of an ombudsman?

Ms. ROHERTY. It is the role of the ombudsman, and I don't know why they're not here. But I can say that they're really under—it's a very underfunded program. There's a tiny amount of funding that states can use. And they were given most recently in the last reauthorization of the Older Americans Act this new population that

they were supposed to go in and serve, which is the assisted living homes. And it grew so fast that it's very difficult to go in. I don't know the number in Florida offhand, but I would suspect it's fewer than 100 staff that have to go into all of these facilities.

Senator NELSON. Dr. Polivka, you or someone said earlier that the trend is toward these ALFs from nursing homes under the theory, obviously, better quality of life, less expensive—just like home health care. If you can have somebody taken care of in their home instead of having to go into a nursing home, it's cheaper, the quality of life is better, everybody's happier. It's a win-win-win.

So if this is the trend, what we've heard here today are abuses that are even worse than we've heard about abuses in nursing homes. Tell us——

Dr. POLIVKA. Senator, let me respond quickly to the ombudsman issue. And I do not consider myself an expert on the ombudsman program, either nationally or within Florida. But I have learned some things about it since the work group began two months ago. And one thing that needs to be remembered is the ombudsman program is not a regulator—a regulatory program. They are to talk to residents. They are to express and convey the grievances and concerns of residents in facilities.

And they've added the ALF. That's still a developing, maturing process, because that's a new kind of task for them that they're still adapting to. I am really concerned—and I expressed this, Senator, to the legislature in Florida, both the House and the Senate, back in March, as they talked about Medicaid reform, as they talked about moving towards a managed long-term care system, which is something I have tracked closely for about 20 years.

I am concerned that as we move in that direction, and we look to contain costs in large measure by containing nursing home use and shifting more and more people into the community residential programs like assisted living, that if we're not careful, we're going to end up with something like a slightly less expensive nursing home, a slightly less regulated nursing home. And that's not going to, I think, meet the needs of anybody, either the residents, policy makers, families, or anybody else. That has—we have to keep a close eye on that possibility and keep it from happening.

Senator NELSON. That's exactly the message that I've gotten here. I mean, I can't say it any better than you just said it. And, interestingly, if the ombudsman program is federal, setting up and giving to the states, and if it's supposed to be vital in advocating for the seniors, then is there an independence in reality for this ombudsman?

And I'd like the record to reflect, and we will submit into the record a statement by Brian Lee, the Executive Director for Families for Better Care, who recently served as Florida's ombudsman.

Senator NELSON. So what should we at the federal level do, in your judgment, in order to see that the ombudsmen can do their jobs more effectively so that these horror stories that we've heard about won't happen, and so that the vast majority of ALFs that are doing a good job don't get painted with the tar brush of all the bad ones?

Ms. ROHERTY. I think that Larry's point is a very significant one, and that is that the ombudsman is only one part of the solution.

It has to work in more of a systemic system in order for it to ensure quality and safety for the consumers. And I think it's—and sometimes you're going to end up calling in the Adult Protective Services if it gets that dire a situation.

In most of the states, they also work with their survey and certification team, so if they're finding things, they're going to call in—the folks that do the regulatory findings—and advise the CMS folks of a real difficult thing. You can't just pick one program and expect them to do everything and fix this whole assisted living issue.

Dr. POLIVKA. Senator, as a follow-on to Martha's point, I don't think we should expect the ombudsman program, either in current or some kind of revised form, to be a substitute or even a major add-on to the regulatory framework. They are there to be in touch with residents. They are there to convey information and occasionally to move information along if they spot something that is really a problem to either the Adult Protective Services or back to the regulatory agency.

I think they need strengthening in playing that role. I think there needs to be a few more resources, and this may be something that the Congress will want to look at as you look at the Older Americans Act, which, I think, is on your agenda now. But I don't think it would be wise to think that the ombudsman program in any other form is going to deal with some of the regulatory issues we've been talking about here today in any definitive way.

Mr. JENKENS. Senator, I'd like to add to that as well and really agree with Martha and Larry. I think the system we have in place depends on multiple checks and balances. The ombudsman program is one of those. But certainly the check and balance between state and federal is the other. And I think that what we know is we all—each of us need someone to hold us accountable to be better than we are ourselves.

That happens in our lives. That happens between providers and state regulators. I worked for a multistate provider. We benefited by state regulators holding us to a higher standard. And I have seen the federal government play that role with states and providers as well.

And I'd like to make a comment. Running a program that asks for an entirely different model to be implemented, which people believe is not possible under the current regulatory structure—I'd like to say that I have found federal regulators to be some of the most flexible and innovative regulators when we are implementing the Green House Project. And, in fact, they often help hold states to a higher standard of flexibility in interpretive guidance than we might get otherwise.

So I don't think it's true that the federal government will squash innovation. But I think it's very important how we approach this and what that partnership looks like, including involving a very significant stakeholder group of providers and advocates to help find the right solution, which we've done before and I know we can do again.

Senator NELSON. Well, on the basis of what we've seen in this newspaper report, the regulatory agency in this case—AHCA in the

state of Florida, the Agency for Health Care Administration—wasn't doing its job.

Mr. JENKENS. I would agree.

Senator NELSON. So the laws weren't being enforced. Now, other than tuning up the ombudsman to blow the whistle, what do we do to get the states to enforce their laws?

Mr. JENKENS. I think we need to give CMS many of the intermediate sanction opportunities that Barbara recommended, and we need to give them some funding to be more effective in playing that role.

Senator NELSON. Mr. Maag, what do you think from your perspective?

Mr. MAAG. Well, I think, Senator, you did hit on at the beginning of that Miami Herald article when you talked about "the regulators allowed"—and it is a matter of not coming up with new regulations but ensuring that the enforcement activities and the regulations that already exist in all the states are actually enforced. It's sometimes a resource allocation.

I think CMS may play a role in that, because many of the states—you mentioned California earlier. One of the reasons that California has a four or five-year wait between inspections is simply a resource allocation issue that they've been facing, and they've chosen to not fund that aspect of the regulatory enforcement process as much as many of us would like to see.

So I think that the role, as Robert said and as Larry said, of having, you know, the oversight to monitor that the states are, in fact, doing what they're supposed to do under their regulatory framework really is a key consideration. There is the tool there—there are the tools there. There are the enforcement mechanisms, and there are many states that are very aggressive and active in it.

As I mentioned, Senator Kohl's home state of Wisconsin is a shining example of a very good regulatory framework, and I think we can use those examples to illustrate how—as a good practice that other states need to start to look at and make sure, by oversight, that they, in fact, are following those kinds of practices.

Dr. POLIVKA. Senator——

Senator NELSON. Go ahead, Doctor.

Dr. POLIVKA. As a follow-up in response to your question, I think that the thing—the work group is looking at at least three areas where we think we can move in the direction that you're talking about. One is limited discretion, possibly, in some decisions that can be made by the regulator, by AHCA. We have not—there's not a consensus on this, but it is being discussed, and it may be something that we will look at both next week and then longer term.

We're very much interested in a progressive sanction kind of model, and it's one that Wisconsin has done a very good job, in my judgment, in looking at that up close over the last couple of months. The other is to get Adult Protective Services—I think Martha or Barbara mentioned—more involved in this.

And we have a list of recommendations we're going to address on Tuesday regarding the relationship between Adult Protective Services, which is in a separate department from Medicaid—bringing them closer together so that they're much—so that not only do they share information, but there's some accountability between those

two organizations in terms of taking actions when a problem is identified.

And the other one is involving the state's attorney's office and law enforcement. That's a bit tricky, and I think it was mentioned a minute ago in terms of problems with evidence and how you proceed with some of these cases. But we're looking at that very closely as well, because we think there's some potential there. There have been two or three cases where the attorneys general have been very effective in Florida in bringing actions.

Mr. JENKENS. I think it would be also worth stating the obvious. This is not just a Florida problem. This could happen to any state in the United States.

Senator NELSON. Well, let me ask you an essential question. Should CMS have the authority to shut down ALFs when chronic problems are occurring and state regulators have failed to act?

Ms. EDWARDS. Senator, if I could at least start, I guess I would just remind all of us that CMS is not the principal payer in assisted living facilities. And there are probably many assisted living facilities across the country in which there are no Medicaid dollars coming at all. And so I'm not sure CMS has the right involvement with this industry, at least today, to be effective.

Senator NELSON. But it sounds like on the testimony that more and more, there is Medicaid dollars going in ——

Ms. EDWARDS. But it could only be a very small portion, and we might find ourselves no longer welcome if we become the vehicle for all regulation. So I would just point out that at this point, there really is a very large assisted living industry. Right now, Medicaid's engagement with them is small, possibly growing. But I just want to keep that in perspective.

Senator NELSON. Well, aren't some things blurring now between nursing homes and ALFs? Haven't we seen here today examples of complex medical services? People who have that need are being admitted to ALFs, whereas, normally, they would be admitted to a nursing home?

Dr. POLIVKA. Senator——

Senator NELSON. So how do we prevent ALFs from becoming unregulated nursing homes?

Dr. POLIVKA. As I mentioned, that's a concern that I and some of my colleagues in Florida have as well, Senator. I don't think at this point—and looking at data, because part of the operation that I administer includes a large data operation for the state of Florida and the Medicaid program. And what I have seen over the last 10 years and have seen as recently as 2010 is that there is a clear difference between the typical assisted living resident, Medicaid supported, and the typical nursing home resident, which is—and those residents have a tendency—or patients have a tendency to be more impaired, require significantly higher levels of care still.

The issue, however, is that there is movement, and it's not just a creep, but steady movement towards the blurring that you're talking about, and that we do have at this point a substantial percentage of people in assisted living who would have been in nursing homes 10 or 15 years ago. That is something we need to be alert to in the way that I mentioned and that you talked about.

Mr. MAAG. And, Senator, I'd like to add—I don't think the assisted living would be considered unregulated nursing homes. They are a very regulated set of communities.

The states that are moving forward on what we commonly call aging in place recognize that, and I can think of states like my home state of Washington, Oregon, some of the others who have allowed additional aging in place—have done that, recognizing that that heightens the awareness of what needs to be done to monitor those states. And they have done, by and large, a very good job of monitoring what goes on in those assisted living communities which choose to provide higher levels of care.

Some assisted living communities don't believe that they have the proper qualifications to provide care to those types of residents, and so those residents aren't in those communities. But those who choose to provide that higher level of care are looked at and scrutinized, knowing that the risk is higher.

Mr. JENKENS. And I would add, Senator, I think from my perspective it's important that the lines have become blurred. It's important that we give people options in where they can be served when they have a nursing home level of need. And some states have done a very good job as they've introduced Medicaid waiver programs, which require people to be nursing home eligible, in actually layering on a regulatory level or category within assisted living to deal with the additional needs around guarding against abuse and neglect and care.

Arkansas is a terrific example of that. They introduced an Assisted Living II category when they introduced their Medicaid waiver program. So I think it's really a question of the system that fits the state, with some federal guidance and then some federal accountability to be sure that those pieces are in place.

Ms. ROHERTY. Senator Nelson, can I just add on—one additional point is that one of the other parts, getting back to the whole system that is in place, if you take—separate out again from CMS and go over to the Administration on Aging, one of the things that is critical to putting—or having an individual choose which place is the proper place is to have options counseling through a third party information and referral specialist that can actually look at the options for the consumer and make sure that what facility they're choosing is going to best meet their needs.

And oftentimes that's not happening. Frequently, individuals need it really quickly. They move from being able to stay at home without extra supports into a situation where, very quickly, they have to make a decision. And so having additional support of third party options counselors would be very helpful.

Dr. POLIVKA. Senator, let me—I think that's a very good point, and the Congress and CMS and AOA have done a good job over the last several years in developing the Aging Adult and Disabled Adult Resource Centers that can provide that function and do in many states, including Florida.

Let me just say, too, that there are a lot of people in assisted living who don't want to leave. And as they become more impaired, there's enormous pressure, but they don't want to leave. And many facilities are running a risk in keeping them there because they have become part of the family, possibly, so to speak, and it creates

a really difficult dynamic related to all the issues that we're talking about.

Mr. JENKENS. People also don't want to leave assisted living because the option of many nursing homes is not an option that they would choose. The institutional environment is tough. And Green House is trying to change that, but that's going to be a big and long change. So I do think we want to make options and choices work with appropriate oversight, given what providers are committing to.

Ms. EDWARDS. Senator, if I could just add, again, a reminder that—because this is like "welcome to how difficult this issue is"—is to remember that much of the movement toward home and community-based services, certainly in the Medicaid program, has, in fact, been driven by consumers themselves who have said, "I don't want a nursing home. I don't want it because the quality of life there is not the quality of life that I want.

"I don't want to live in an institutional setting where I don't get to choose how I spend my day, who I spend my time with. I don't have the ability to take some risks in my own life, even though I prefer the quality of life if I can stay in my own home, if I can stay in my own apartment, if I can choose a less restrictive setting."

And the movement has really been driven by consumers themselves who are saying, "I want more choices. I want more autonomy and independence. And while I might be safer in another setting, that's not a quality of life that I want for myself or my loved one."

And so part of the challenge here is trying to assure that as we work toward caring—being sure that people are well cared for and are not subject to abuse and neglect and the horror stories that we've heard today is also recognizing that what people don't want is to live in a nursing home if, in fact, they have other choices that can meet their needs. And so it's just a matter of keeping in mind that balance, or finding better models of oversight.

Senator NELSON. Well, I want to thank all of you for a very lively discussion. I think it has enormously added to the repository of information of this committee. And let's see what we can do, at least, to make the suggestions to the states for the ombudsmen to be more effective, and, secondly, that because of the abuses that have been uncovered, albeit in a small, small percentage of the ALFs, that we find a better way at encouraging the states to take regulatory control of this problem and do what they should under their laws, that is, regulate so that the people's conditions are what the community at large would accept.

And, of course, what the Miami Herald chronicled was not conditions that the community would accept at all—to the contrary, to the point of absolute shock and revulsion.

Mr. Navas, I'm sorry you had to go through your personal experience. But you brought that personal experience here to this committee, and we are very, very grateful for that.

Thank you, and the hearing is adjourned.

[Whereupon, at 4:02 p.m., the hearing was adjourned.]

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APPENDIX

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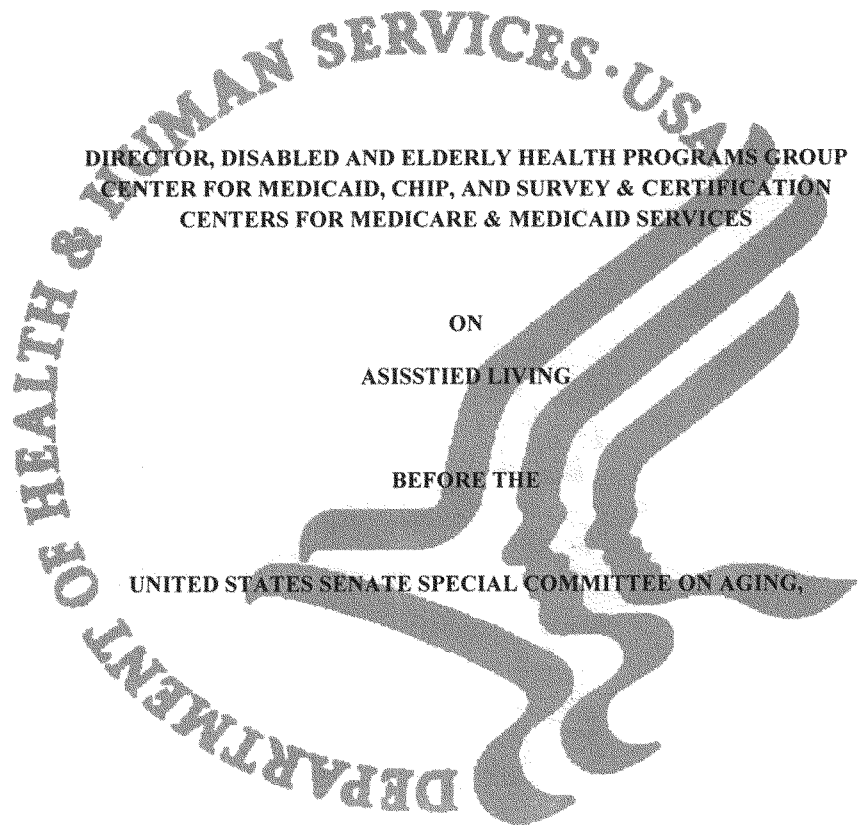
STATEMENT OF

BARBARA COULTER EDWARDS



DIRECTOR, DISABLED AND ELDERLY HEALTH PROGRAMS GROUP
CENTER FOR MEDICAID, CHIP, AND SURVEY & CERTIFICATION
CENTERS FOR MEDICARE & MEDICAID SERVICES

ON

ASISSTIED LIVING

BEFORE THE

UNITED STATES SENATE SPECIAL COMMITTEE ON AGING,

NOVEMBER 2, 2011

U.S. Senate Special Committee on Aging
Hearing on Assisted Living
November 2, 2011

Senator Nelson, Chairman Kohl, Ranking Member Corker, and members of the Committee, thank you for the invitation to discuss how the Centers for Medicare & Medicaid Services (CMS) can support States in offering the kinds of long-term care options for Medicaid beneficiaries that promote independence and choice, and assure that they have the opportunity to live in and fully participate in their communities.

Background

For most individuals, long-term care is provided by family members and friends who receive no payment for their services. Others turn to professional assistance, ranging in degree from a home health aide who visits several times a week in their own homes to assist with meal preparation and household chores, to adult day care, to an assisted living facility, or, for those in need of 24-hour nursing care, to a nursing home. For non-elderly individuals with disabilities, long-term services and supports may include occasional or ongoing support staff assistance with activities of daily living, employment related or other day supports, group homes, adult foster care, caregiver respite options, and intermediate care facilities for individuals with intellectual disabilities.

Not all Americans who need long-term services and supports have family members and friends who are able to provide the necessary care. Medicare, which is not a long-term care program, is not a source of primary support. Medicaid, which can provide a broad array of long-term services and supports for eligible individuals who need these supports, has become an indispensable resource for those with long-term care needs who are unable to pay for the full cost of services. Medicaid is the largest purchaser of long-term services and supports in the nation, paying about 62 percent of the $203.2 billion spent on long-term care services in fiscal year 2009. Of the total amount Medicaid spent on long-term services and supports in 2009, about 45 percent was spent on home and community based services (HCBS) and 55 percent on institutional care. In comparison, only about 24 percent of Medicaid long-term care spending was directed towards home and community based services in 1997.[1]

[1] http://www.nhpf.org/library/the-basics/Basics_LongTermServicesSupports_03-15-11.pdf

As you know, Medicaid is a shared partnership between the Federal Government and the States. The Federal Government provides financial matching payments to the States, conditioned on each State designing and running its own program consistent with the Federal statute. State governments have a great deal of programmatic flexibility to tailor their Medicaid programs to meet the needs of their beneficiaries within their unique political, budgetary, and economic environments. As a result, there is considerable variation among the 50 States in eligibility, services, and reimbursement rates to providers and health plans. States are responsible to design the scope of their benefit within Federal standards, enroll beneficiaries, license and contract with providers, set reimbursement rates, negotiate managed care contracts, and provide oversight of access and quality.

State-designed Medicaid programs of long-term services and supports offer services in a variety of settings, delivered by a variety of providers, to individuals with diverse needs. Individuals in need of this type of care may be frail elderly Americans or younger Americans with significant physical, intellectual, developmental, or mental disabilities. CMS seeks to ensure that all long-term care is person-centered, appropriate for each individual's unique physical and social needs, and allows aging-in-place when appropriate.

State Flexibility Regarding Assisted Living Facilities

The term "assisted living facilities" usually refers to residential housing facilities that provide individuals with personal care and other supportive services to assist with the activities of daily living, as well as social and recreational programming and medication assistance. Depending on State licensure laws, some assisted living facilities may even provide 24-hour nurse access on-site or have a nurse on call. Generally, all provide less intensive 24-hour services designed to ensure residents' supervision and security.

CMS does not define what qualifies as an assisted living facility, nor is assisted living defined consistently among the States. Depending on the State, assisted living facilities may take the form of group homes, adult day or foster care, or senior living communities. Assisted living facilities therefore can vary in terms of the population served (residents may include elderly individuals with disabilities or a need for assistance in activities of daily living, or younger persons with cognitive,

behavioral health, or physical disabilities), size (a 4-person group home or a large complex with many apartments or living units), and payer mix (some facilities have mostly private pay residents, while other may serve large percentages of individuals with Medicaid coverage).

States also have significant discretion regarding the types of home and community-based long-term services and supports, such as "assisted living" supportive services, that they provide to Medicaid beneficiaries. Unlike nursing home care, which States are required to provide under Federal Medicaid law, State Medicaid programs are not required to cover services offered at assisted living facilities, even for residents who are otherwise covered by Medicaid. Many States choose to reimburse assisted living facilities for services that assist individuals in the activities of daily living to provide a community-based alternative to institutional care for individuals who prefer to delay or avoid nursing home care, but can no longer remain in their own private homes.

Again in contrast to nursing home services, Medicaid may not cover the cost of "room and board" in any assisted living facility or other community-based residential setting; Medicaid only provides for this type of cost in statutorily defined institutional settings (e.g., nursing homes, hospitals, and intermediate care facilities for persons with intellectual/developmental disabilities).

States can cover HCBS in assisted living settings in several ways. One option is to provide services like personal care under section 1915(c) of the Social Security Act, which authorizes the Secretary of Health and Human Services (HHS) to waive certain Medicaid statutory requirements so that a State may offer HCBS to State-specified target group(s) of Medicaid beneficiaries. In addition, States may use HCBS State plan authorities, like the 1915(i) and 1915(k) options noted below, to cover HCBS in assisted living settings.

There is widespread support for increased flexibility and options for offering HCBS, and Congress has provided new legislative authority and Federal grant programs to help States build their HCBS infrastructure. These tools include expanding the Money Follows the Person (MFP) demonstration, where States received enhanced Federal matching funds to support individuals who can move from living in institutional long-term care settings into integrated community housing. Forty-three States and the District of Columbia are currently participating in MFP, developing infrastructure that better supports community based service options. Other new authorities provided under the

Affordable Care Act include section 1915(i) State Plan authority to offer "waiver-like" services and supports to targeted groups; section 1915(k), Community First Choice, which allows States to offer community attendant services and other HCBS with a 6 percentage point increase in their Federal matching rate; and the Balancing Incentive Program, which offers States which are still heavily dependent on institutional long-term care services up to four years of increased Federal matching funds for HCBS to build improved systems that support community based long-term services and supports. Both Community First Choice and the Balancing Incentive Program became available to States on October 1, 2011. To date, approximately 15 States have expressed interest in the Balancing Incentives Program.

Home and Community Based Services Waivers

The vast majority of HCBS are provided in States through section 1915(c) waivers. Section 1915(c) waivers enable States to promote and support community living for Medicaid beneficiaries and, thereby, avoid institutionalization. Prior to the enactment of section 1915(c), the Medicaid program provided for little in the way of coverage for long-term services and supports in non-institutional settings, but offered full or partial coverage of institutional care. Section 1915(c) was enacted to enable States to address the needs of individuals who would otherwise receive institutional care by furnishing cost-effective services (personal care, homemaker services, enhanced nursing or therapies, transition services) to assist them to remain in their homes and communities.

In 1999, the Supreme Court ruled in *Olmstead v. L.C.*, 527 U.S. 581, that States are obligated to serve individuals with disabilities in the most integrated setting appropriate to their needs, and that unjustified institutionalization of people with disabilities is a form of unlawful discrimination under the Americans with Disabilities Act (ADA). This landmark decision marks the first time that the Court interpreted the ADA in a way that directly impacts Medicaid. Generally, under the *Olmstead* decision, States are required to provide for community-based services for persons with disabilities otherwise entitled to institutional services under the State's programs when: 1) community placement is appropriate; 2) the person does not oppose such placement; and 3) the placement can reasonably be accommodated taking into account resources available to the State and the needs of others receiving State-supported disabilities services. Services offered under section 1915(c)

waivers are an important tool for States to comply with the *Olmstead* decision and offer care to Medicaid beneficiaries in the most integrated setting appropriate to their needs.

Forty-eight States and the District of Columbia offer services through HCBS waivers. Arizona and Vermont operate similar programs under section 1115 research and demonstration authority. There is no Federal requirement limiting the number of HCBS waiver programs a State may operate, and currently there are more than 320 active HCBS waiver programs in operation throughout the country. There is also no limit on the number of services that a State may offer in a waiver, nor are States required to include specific services in the waiver, although States must specify the services that will be furnished through the waiver. The waiver authority allows States to limit services to specific regions and to target services to certain groups—strategies normally prohibited under Medicaid. Services provided under 1915(c) waivers complement and/or supplement the services that are available through the Medicaid State plan and other Federal, State, and local public programs.

Because CMS gives each State the freedom to tailor its 1915(c) waiver applications to meet the unique needs of its State, Medicaid coverage of HCBS varies widely between States. And because CMS allows States the flexibility of defining many of the services, terminology varies widely across States. For example, one State's Medicaid program may not cover services offered in an assisted living facility, another may have defined a collection of waiver services as "assisted living supports" and designate assisted living facilities as providers, and a third may reimburse assisted living facilities, as well as other providers, for the supports and services commonly thought of as "assisted living," but refer to these services by another term like "personal care" or "community supports." Additionally, such services may be targeted to specific populations with different eligibility requirements.

Federal Regulation of Nursing Homes vs. HCBS Providers

Federal Medicaid participation requirements for providers offering services under a 1915(c) waiver are significantly different from Medicaid participation requirements for nursing homes and other institutional long-term care settings. These differences are based in differences in Federal law and regulation. Nursing home services have been specifically defined in Medicaid and Medicare

through a long legislative history, most notably the OBRA '87 Nursing Home Reforms, which remain the structure for Federal regulations and CMS policy. Medicare covers rehabilitation and skilled nursing home care; Medicaid nursing homes similarly offer skilled care and rehabilitation, and also long-term care. Federal law establishes nursing homes as comprehensive, all-inclusive services that provide total care including housing and nutrition. In order for a nursing home to receive Medicare or Medicaid payments, State inspectors must certify that the nursing home meets CMS-established regulatory requirements that address over 180 aspects of care based on expectations that Congress set forth in law. Through the Federally–funded Survey and Certification program, CMS contracts with the survey agency in each State to certify that nursing homes meet these requirements. Health and fire safety inspections of these certified nursing homes take place about once a year, but may be done more often to investigate complaints or if the nursing home is performing poorly.

Licensing of assisted living facilities (and other HCBS providers), on the other hand, is a State responsibility, and there are no Federally-established standards. Monitoring of such facilities is also generally a State responsibility. Lacking a basis in law or practice, CMS does not have a direct role to define or oversee "assisted living facilities" as a category or provider type. However, CMS does require certain standards for any services offered under State Medicaid programs, particularly for 1915(c) waivers, under which the majority of services in assisted living facilities are covered in the Medicaid program. CMS requires States to specify and define services to be offered under each 1915(c) waiver and to identify the qualifications of providers who may bill for those services. If a State proposes to reimburse for supportive services provided in assisted living facilities, a State must demonstrate that it has adequate provider licensure requirements and oversight systems in place.

Efforts to Ensure Participant Health and Well-Being in Section 1915(c) Waivers

State Waiver Assurances

While there are no specific licensure requirements for HCBS providers, section 1915(c) and its implementing regulations require that the State demonstrate several "assurances" regarding their waiver programs. As specified in 42 CFR 441.302, these assurances relate to participant health and welfare, appropriate level of care needs, effective evaluation of need, adequate service plans, availability of qualified providers, and financial accountability. CMS is committed to safeguarding the health and safety of Medicaid beneficiaries.

In its waiver application, a State must demonstrate that it is prepared to protect participants in a number of ways, including by:

- Specifying the qualifications of waiver providers and verifying that providers continuously meet these qualifications;
- Periodically monitoring the implementation of the service plan and participant health and well-being;
- Identifying and responding to alleged instances of abuse, neglect and exploitation that involve waiver participants; and,
- Instituting appropriate safeguards concerning practices that may cause harm to the participant or restrict participant rights.

Quality Improvement Process

In addition to detailing how it will accomplish these tasks, a State must specify how it monitors performance in assuring health and well-being by preparing and submitting a Quality Improvement Strategy that, on an on-going basis, identifies, addresses, and seeks to prevent the occurrence of abuse, neglect and exploitation.

The Quality Improvement Strategy is a process that involves continuous monitoring of the implementation of each waiver assurance, methods for remediation or addressing identified individual problems and areas of noncompliance, and processes for a) aggregating collected information on compliance and remediation activities, and b) prioritizing and implementing needed systems changes to improve care.

The Reporting Process

To satisfy Federal monitoring requirements, States must submit evidence that they are meeting the statutory and regulatory assurances, as well as annual reports that include information on the health and well-being of HCBS participants and a final report in the year prior to the expiration of the waiver. Combined with information obtained by the CMS regional office throughout the waiver period, the regional office makes a determination about the State's performance and communicates it through the draft report, discussed in more detail below.

In certain circumstances, including when the health and well-being of waiver participants may be jeopardized, CMS may find it necessary to conduct special or focused on-site or off-site review activities. The results of this type of review may necessitate the State's preparing and implementing a corrective action plan.

The Renewal Process

Continuation of a waiver beyond its initial three-year or five-year approval period requires that the State submit a five-year waiver renewal application and a determination by CMS that, while the waiver has been in effect, the State has satisfactorily met the waiver assurances and other Federal requirements, including the submission of a mandatory annual waiver report (the CMS-372(S) report). The Affordable Care Act allows waivers for services provided to individuals who are dually eligible for Medicare and Medicaid to have five-year initial and subsequent approval periods, subject to the Secretary's discretion.

At least one year in advance of the expiration date of an approved waiver, the CMS regional office will issue a draft report to the State summarizing its findings and conclusion. If the draft report concludes that one or more requirements of the waiver are not met, then the regional office must provide the basis for the conclusion. In its response to the draft report, the State may dispute the regional office findings or propose a course of action to remediate the problem, either immediately or by implementing a corrective action plan. If the State does not propose a satisfactory course of action, CMS may not approve the State's HCBS waiver renewal application. Because waiver termination could have a significant detrimental impact on all participants receiving waiver services, CMS works diligently with States to achieve full compliance.

In response to State feedback and Federal concerns, CMS has recently engaged with our State partners in a review of the waiver quality improvement and reporting process in order to identify opportunities to improve the effectiveness and efficiency of State and Federal efforts to improve care and assurance of safety of waiver participants.

Rulemaking on HCBS Waivers

CMS has been engaged in the development of updated regulations regarding section 1915(c). In the June 22, 2009 Federal Register (74 FR 29453), CMS published the Medicaid Program HCBS advance notice of proposed rulemaking (ANPRM) that proposed to initiate rulemaking on a number of areas within the section 1915(c) program. The purpose of the ANPRM was to solicit input from a broad array of stakeholders regarding opportunities to improve the quality of HCBS offered under the 1915(c) programs. CMS received 313 comments from States, health care and community support providers and associations, consumer groups, social workers, and others, plus held teleconferences with stakeholders to solicit additional feedback. CMS followed up with a notice of proposed rulemaking (NPRM), CMS–2296–P (42 CFR Part 441), which was published in the Federal Register on April 15, 2011, with a 60-day comment period. These proposed regulations address key issues raised in the ANPRM, including improvements in person-centered planning, clarifying characteristics of home and community-based settings, and providing improved tools for CMS to use to assure compliance with health and well-being expectations.

Person Centered Planning and Clarifying the Characteristics of HCBS Settings

Underpinning all aspects of successful HCBS is the importance of a complete and inclusive person-centered planning process that addresses health and long-term services and support needs. In recognition of the importance of person-centered planning, CMS–2296–P proposes requirements for elements of person-centered planning and approaches to service delivery. The planning process would be conducted in a manner that reflects both what is important for the individual to meet identified clinical and support needs, determined through a person-centered functional needs assessment process, and what would reflect personal preferences and choices and contribute to the assurance of health and well-being. The plan resulting from this process would include individually identified goals, the services and supports that will assist the individual in achieving these goals, and identify risk factors and measures in place to minimize them.

Through CMS–2296–P, CMS also proposed to improve the assurance that HCBS are truly "home and community-based" in nature and provide a meaningful alternative to an institutional experience of care. Setting characteristics that may not be home and community based include regimented meal and sleep times, limitations on visitors, lack of privacy, and other attributes that limit an individual's ability to engage freely in the broader community. In addition, encouraging "aging in

place," or allowing individuals to remain where they live as they age and/or support needs change, is a proposed requirement for assisted living settings for the elderly.

CMS Strategies to Ensure Compliance with Statutory Assurances

At present, if CMS identified serious quality issues, such as potential harm to individual health and well-being or significant financial concerns, and States failed to take appropriate remedial action, the only enforcement options addressed in the regulations would be for CMS to refuse to renew a State's waiver or terminate the waiver.[2] Such action could have a significant detrimental impact on the individuals served (for example, loss of waiver services or Medicaid eligibility).

CMS is interested in working with States to achieve full compliance without having to resort to termination of a waiver. Specifically, in CMS-2296-P CMS proposed to add language describing additional strategies CMS may employ to ensure State compliance with the requirements of a waiver, short of a waiver termination or non-renewal. CMS's proposed regulation at the new section 441.304(g) reflects an approach to encourage State compliance.

These strategies include use of a moratorium on waiver enrollments or withholding of a portion of Federal payment for waiver services or for administration of waiver services in accordance with the seriousness and nature of the State's noncompliance (that is, health and well-being concerns and significant financial issues). These strategies could continue, if necessary, as the Secretary determines whether termination is warranted. CMS' primary objective is to use such strategies rarely, only after other efforts to resolve issues have not succeeded as necessary to ensure the health and well-being of individuals served.

Once CMS employs a strategy to ensure compliance, the State must submit an acceptable corrective action plan in order to resolve all areas of noncompliance. The corrective action plan must include details on the actions and timeframe the State will take to correct each area of noncompliance, including necessary changes to the quality improvement strategy and a detailed timeline for the

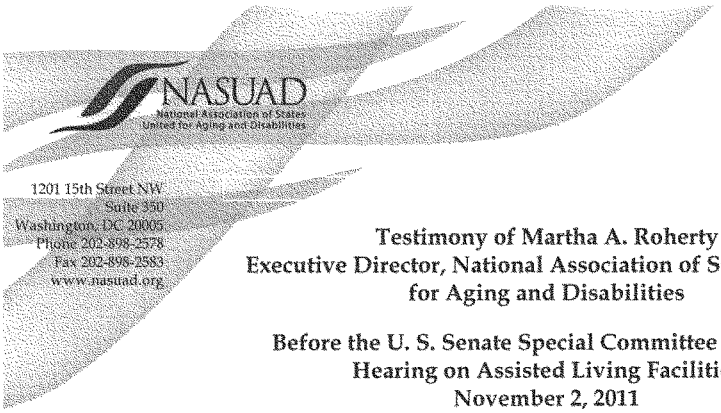
[2] This authority and the process for termination of waivers are currently addressed in the regulations at sections 441.304(d), 441.307, and 441.308.

completion and implementation of corrective actions. CMS will determine if the corrective action plan is acceptable.

CMS invited comment on the discussion of characteristics of HCBS and compliance strategies in proposed rule CMS–2296–P during the 60-day comment period that ended on June 14, 2011. CMS is currently reviewing over 1600 comments received during the comment period on the proposed rule. Over half of these comments addressed the proposed characteristics of home and community based settings, indicating support for many provisions as well as opposition to those same provisions. Comments raised issues regarding the importance of allowing services and settings to reflect the specialized needs of individuals (e.g., those with cognitive or memory care needs) and raised questions regarding the meaning and impact of certain proposed standards. CMS is reviewing all comments closely and is committed to continuing a dialogue with all interested stakeholders on issues related to designing services and supports that meet individual needs, and that offer meaningful opportunities for individuals to be served in the most integrated community settings appropriate to their needs and preferences.

Conclusion

Thank you for the opportunity to draw attention to CMS efforts to provide Medicaid beneficiaries with quality services in their homes and communities, including in assisted living environments. Regardless of the care setting or payer, all Americans need access to high-quality, flexible, and personalized long-term care supports and services. CMS is committed to continuing our current efforts to engage consumers, caregivers, providers, and States in this effort to better support the design and delivery of long-term care supports and services that enable individuals with cognitive and physical impairments to have access to quality long-term care in their homes and communities.



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Testimony of Martha A. Roherty
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Before the U. S. Senate Special Committee on Aging
Hearing on Assisted Living Facilities
November 2, 2011

On behalf of the National Association of States United for Aging and Disabilities, I would like to thank the Senate Committee on Aging for the opportunity to testify at this hearing on assisted living.

NASUAD was founded in 1964 under the name National Association of State Units on Aging (NASUA). In 2010, the organization changed its name to NASUAD in an effort to formally recognize the work that the state agencies were undertaking in the field of disability policy and advocacy. Today, NASUAD represents the nation's 56 state and territorial agencies on aging and disabilities, and supports visionary state leadership, the advancement of state systems innovation, and the articulation of national policies that support home and community based services for older adults and individuals with disabilities.

The Association's mission is to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability and their caregivers. Our statement is based on the Association's mission to foster the development of state long-term services and supports systems (LTSS) that support individuals of all abilities and ages as well as their families.

While NASUAD member state agencies' roles vary from state to state, Association members develop and operate Medicaid-financed assisted living services in collaboration with their partners in the Single State Medicaid Agency (SSMA), oversee assisted living operations in the context of Medicaid quality monitoring strategies, lead or participate in affordable assisted living program development. Later in my testimony, I will discuss Medicaid Section 1915(c) Home and Community Based services (HCBS) waiver quality oversight in more detail. However, it is important to note that only a small portion of

assisted living is financed by Medicaid; the vast majority of assisted living is privately financed.

Related to the point above, NASUAD member state agencies provide assistance to people seeking Medicaid-financed assisted living and private pay assisted living. Specifically, NASUAD members provide resident advocacy services through Adult Protective Services (APS) and State Long-Term Care Ombudsman (SLTCO) programs, and also deliver information about assisted living as an LTSS option via information and referral (I&R) programs and Aging and Disability Resource Centers. With the exception of Medicaid – financed assisted living services program functions, including Medicaid Section 1915(c) waiver quality monitoring requirements and Medicaid waiver eligibility, most of these assisted living-related functions are performed for both private and publicly financed assisted living. States also license or certify assisted living settings, though the responsibility for licensure or certification is often located in a separate division within an umbrella health and human services agency, or in a separate department.

As outlined below, please find NASUAD's statement relating to the existing and potential funding sources for the State Long-Term Care Ombudsman Program and APS, as well as the opportunities for these initiatives to enhance the quality of life for residents of assisted living facilities, and the barriers to successfully doing so, as well as NASUAD's recommendations for improving the current system of assisted living.

Ombudsman Program Activities in Assisted Living Facilities

Often, the ombudsman program is only associated with advocacy for residents of nursing homes, despite the Older American's Act (OAA) requirement that all State Long-Term Care Ombudsman Programs serve residents in other settings, including assisted living facilities. In fact, ombudsman program advocacy on behalf of residents in assisted living facilities ranges from consumer education initiatives to complaint investigations.

Increasingly, long-term care residents live in residential settings other than nursing homes. While the number of beds and facilities in nursing homes have been steadily declining for several years, the growth of beds in other residential settings, including assisted living facilities, is steadily increasing. In 2005, there were 1.8 million beds in licensed nursing homes and 1 million beds in board and care and other settings. In the following years, these numbers trended downward and upward, respectively, so that by 2010, the most recent year for which data is available, there were 1.7 million beds licensed in nursing homes and 1.2 million in board and care and other settings.[1] Federal policy continues to accelerate the growth of home and community based long-term care services, and as the number of residents in other residential settings continues to approach the numbers of residents in nursing homes, the importance of the ombudsman's role in assisted living facilities will also increase. In many states, Medicaid funding provides services in these non-nursing home

[1] NORS Data for FY10, Table A-6

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residential settings as part of the Home and Community Based Services array, often through a waiver.

Medicaid Waiver

Most states use one or more Medicaid Home and Community Based Services waivers (1915(c)) to help older adults and individuals with disabilities continue to live independently in their homes and communities. Under Medicaid waivers typically serving older adults, individuals must meet the state's nursing home level of care, and waivers may not be used to pay for room and board in residential settings such as assisted living. Whether or not a person's care needs can be adequately met in an assisted living setting is handled on a case-by-case basis, and individuals who are eligible for waiver services typically have a case manager assigned to assist them with accessing needed services.

Some states use Home and Community Based (HCBS) waivers that provide services to individuals in residential care settings as part of a larger initiative to transition individuals out of nursing facilities, or to provide individuals who are at risk of institutionalization with options for remaining in their communities. A 2005 report, Quality in Medicaid Waiver Assisted Living: The Ombudsman Program's Role and Perspective, highlights the way assisted living waivers work in different states, ombudsman program activities in assisted living, and quality of care in assisted living, by focusing on the experiences of seven states using such waivers for these purposes.

A 2007 overview of residential care and assisted living policy found that 42 states had the option of using Medicaid funds to provide services for individuals in residential care settings, including assisted living facilities. The majority of these states, 28, covered assisted living services through a Medicaid waiver, while seven used the Medicaid state plan, and six states used a combination of waivers and the state plan.[2] Two years later, in 2009, a report on State Medicaid Reimbursement Policies and Practices in Assisted Living found that in that year, 37 states used 1915(c) HCBS waivers to cover services in residential settings, 13 states used the Medicaid state plan services, four included services in residential settings under 1115 demonstration program authority, and six states used state general revenues.

Concerns about quality and oversight have been raised as growth in assisted living has outpaced states' efforts to define and regulate the industry in many states, and ombudsmen continue to be called upon to resolve complaints about quality of care and residents' rights on behalf of assisted living residents. With respect to Medicaid HCBS waivers, the role of the ombudsman in assisted living facilities may be to inform consumers of waiver services within the context of providing information about long-term care options, while others also coordinate with agencies that administer Medicaid waivers.[3] In FY10, the ombudsman program nationwide handled 51,163 complaints on behalf of residents in assisted living and

[2] Residential Care and Assisted Living Compendium: 2007
[3] Quality in Medicaid Waiver Assisted Living: The Ombudsman Program's Role and Perspective

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similar type facilities, a slight seven percent decrease from 55,029 in FY09. In comparison, complaints against nursing homes decreased by about ten percent from 176,083 in FY09 to 157,962 in FY10.[4]

In Section 1915(c) Home and Community-Based Services (HCBS) waivers, states are required to develop quality improvement strategies for all services delivered under the waiver, including assisted living. CMS has designed and adopted an evidence-based approach to HCBS Waiver program quality. The evidence-based approach is premised on the expectation that states have first-line responsibility for program monitoring to ensure the waiver operates as it was designed, and that the health and welfare of program participants are protected. States, on a periodic basis, must provide CMS with evidence that the program is indeed operating as specified in the approved waiver and that participants' health and welfare are maximized. The evidence CMS requires is tied to the six statutory assurances that states pledge to CMS as a condition of approval of a waiver. CMS' role is to review the evidence the state submits, along with other information about the waiver's performance, and render a determination about the Waiver's compliance with the federal assurances. [5] For several of the assurances CMS has articulated sub-assurances which operationalize CMS' interpretation of what assurances mean, further define the assurances, and are intended to ensure that states monitor the aspects of the program CMS deems fundamental.

It is important to note that these quality oversight requirements only address Section 1915(c) Medicaid waivers. While CMS has indicated long-term plans for its quality approach to cut across Medicaid HCBS program authorities such as the Medicaid Section 1915(i) State Plan Option and Section 1115 Research and Demonstration Waivers, such requirements do not apply to private pay facilities or residents.

In recent years, the number of sub-assurances and methods of addressing Section 1915(c) continuous quality improvement has been problematic for states. As a result, NASUAD and its sister association, the National Association of State Directors of Developmental Disabilities Services (NASDDDS), transmitted a letter to CMS communicating these concerns. In response, CMS is working with NASUAD and NASDDDS to convene a work group composed of state officials (e.g., aging and physical disabilities, intellectual and developmental disabilities, and state Medicaid agency), national association staff, and CMS. The workgroup is ongoing, and met virtually for the first time in September 2011 to re-conceptualize how quality is monitored and reported to CMS.

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[4] NORS Data for FY10, Tables B-1 and B-6

[5] The six statutory Medicaid waiver assurances are: 1) Level of Care: Persons enrolled in the waiver have needs consistent with an institutional level of care; 2) Service Plan: Participants have a service plan that is appropriate to their needs and preferences, and receive the services/supports specified in the service Plan; 3) Provider Qualifications: Waiver providers are qualified to deliver services/supports; 4) Health and Welfare: Participants' health and welfare are safeguarded; 5) Financial Accountability: Claims for waiver services are paid according state payment methodologies specified in the approved waiver; and 6) Administrative Authority: The State Medicaid agency is actively involved in the oversight of the waiver, and is ultimately responsible for all facets of the waiver program.

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Medicaid Administrative

Historically, State Long-Term Care Ombudsman Programs have had agreements with their state Medicaid agencies to carry out "activities the Secretary finds necessary for proper and efficient administration of the state Medicaid plan."[6] According to Section 1903(a) of the Social Security Act, State Medicaid agencies may claim federal Medicaid funds for activities which further the "proper and efficient" administration of the state plan, which is generally for expenses related to providing approved services to Medicaid-eligible recipients as well as Medicaid administrative functions. Administrative activities can include, but are not limited to, outreach activities undertaken to identify and enroll Medicaid beneficiaries; education and engagement of Medicaid members; quality assurance; and providing access to appropriate services at the appropriate time from the appropriate provider at the appropriate setting for the appropriate reimbursement.

The state does not have to link specific activities to Medicaid eligible individuals in order to claim federal Medicaid funds, but they must calculate the administrative costs of a particular service, such as the ombudsman program, which can reasonably be attributed to Medicaid. In 2007, 13 states were drawing Medicaid administrative funding to carry out a variety of activities which assist the Medicaid agencies in administration of the state plan and assist Medicaid residents in ways which are not included in the ombudsman program functions outlined in the OAA.[7] The sustainability of these endeavors is expected to be clarified by CMS in forthcoming guidance.

Home Care Ombudsman

As established by the Older Americans Act (OAA), Long-Term Care Ombudsmen are advocates for residents of nursing homes, board and care homes, assisted living facilities, and similar adult care facilities. In this capacity, they work to resolve problems of individual residents and to bring about changes at the local, state and national levels that will improve residents' care and quality of life. All states, the District of Columbia, Puerto Rico, and Guam have an Office of the State Long-Term Care Ombudsman, and these statewide programs are federally funded under Titles III and VII of the OAA, as well as by other federal, state and local sources.[8]

Under the OAA and its appropriations, the role of the Long-Term Care Ombudsman does not extend to non-institutional settings, despite the growing number of complaints made by consumers receiving home care. According to the National Ombudsman Reporting System (NORS), in FY10, 1,055 home care complaints were made to ombudsmen, an increase over the 774 similar complaints made in FY09, and the 907 made in in FY08.[9]

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[6] Section 1903(a) of the SSA
[7] Unpublished NASUAD survey data
[8] AoA Fact Sheet: Long-Term Care Ombudsman Program
[9] NORS Data, Table B-10

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To address this growing need, some states have looked to other funding sources to expand the scope of their existing OAA-created Long-Term Care Ombudsman Programs so that they may advocate on behalf of consumers who receive home and community based care. As of 2007, 12 states either authorized or mandated under state law that their ombudsman programs serve consumers who receive home and community based care.[10]

A survey of eleven of these programs, supported by the U.S. Administration on Aging (AoA) and compiled in the Home Care Ombudsman Programs Status Report: 2007 identified variances and commonalities in the scope, funding and administration of these programs from state to state.

Scope. Though the full array of services covered by the surveyed Home Care Ombudsman Programs differed, the majority of state programs reported that they were responsible for handling complaints concerning Home and Community Based Services funded by Medicaid waivers, a significant trend given the emphasis on the use of waiver services in states' long-term care rebalancing efforts, including nursing facility diversion and transition activities. Notably, since 2007, two additional states, Georgia and Delaware, have expanded their Long-Term Care Ombudsman Programs to provide in-home ombudsman services through the Money Follows the Person demonstration.

In addition to Medicaid waivers, the most frequently covered services included state funded home care, home health agency services, OAA home care programs, and private pay home care. The programs also signaled that the majority of home care complaints related to issues of access to service, staffing problems, and abuse and exploitation.

Funding. The OAA defines the scope of ombudsman services to include nursing facilities, skilled nursing facilities, board and care and similar adult care homes. Accordingly, funds authorized or appropriated under the OAA for the State Long-Term Care Ombudsman Program may not be used for ombudsman services in settings other than those listed in the act.[11]

Since home care is outside the scope of the ombudsman's duties as enumerated in the OAA, State Long-Term Ombudsmen who advocate for individuals receiving home and community based care must rely on non-OAA dollars to support their work in this area. A majority of the surveyed programs named state general revenues as their single funding source, while five states reported multiple funding sources, including Medicaid waiver funds, Medicaid administrative funds, facility-based provider fees, and state funds dedicated to home care advocacy.

Administration. The majority of states surveyed allowed any ombudsman program staff member to investigate home care complaints, rather than dedicating specific staff to this task, and seven states required ombudsman program staff to receive training on home care

[10] Home Care Ombudsman Status Report
[11] OAA Section 102(a)(32)

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advocacy prior to investigating home care complaints. The survey also revealed that Home Care Ombudsman Programs coordinate both formally and informally with other state agencies regarding home care issues, including with Adult Protective Services agencies for the referral of home care complaints, and with the state agency that licenses and certifies home care providers and Medicaid waiver programs.

Adult Protective Services

While the role of State Long-Term Care Ombudsmen in preventing, reporting and investigating abuse in long-term care facilities varies across the country, Adult Protective Services (APS) is the principal public agency responsible for investigating reported cases of elder and vulnerable adult abuse, and for providing victims with treatment and protective services regardless of setting or service funding source. Although most APS agencies also handle adult abuse cases (ages 18-59), nearly 70 percent of their caseloads involve elder abuse, as APS caseworkers are generally the first responders to such reports.

Scope. APS are those services provided to insure the safety and well-being of elders and adults with disabilities who are in danger of being mistreated or neglected, are unable to take care of themselves or protect themselves from harm, and have no one to assist them. Interventions provided by APS may include, but are not limited to, receiving reports of adult abuse; exploitation or neglect; investigating these reports; as well as case planning, monitoring, and evaluation. In addition to casework services, Adult Protection may provide or arrange for the provision of medical, social, economic, legal, housing, law enforcement or other protective, emergency, or supportive services.

Funding. With no federal funding stream dedicated to the provision of APS, the funding sources for APS varies from agency to agency. According to a 2009 APS State Budget Cuts Survey administered by the National Adult Protective Services Association (NAPSA), 85 percent of APS programs are funded with state funds, 60 percent receive county or tribal funds, while 30 percent are funded with SSBG dollars and another 30 percent rely on Medicaid funds.

The same NAPSA study highlights the degree to which the economic downturn continues to impact the provision of APS, with over half of APS state administrators reporting budget cuts of 13.5 percent in 2009. Troublingly, two-thirds of the respondents also said that abuse reports to APS have increased by 24 percent, leaving vulnerable adults increasingly at risk. These results support the data in NASUAD's joint report with AARP and HMA, Weathering the Storm: The Impact of the Great Recession on Long-Term Services and Supports, which captures a significant and disturbing trend since the beginning of the economic downturn: the large number of states that experienced increased calls for APS in state fiscal years 2010 and 2011. Of these states, 25 reported that financial exploitation was the number one cause of such calls, and an additional 20 states reported that neglect was a factor in the calls. Despite an increase in the number of APS calls, only two states increased funding for APS over this time period, while the rest either flat-funded or decreased state appropriations.

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The ongoing efforts of state APS agencies to absorb these cumulative budgetary cuts highlight the need for federal funding to support these programs. Prior to the passage of the Elder Justice Act (EJA) as part of the 2010 Patient Protection and Affordable Care Act (ACA), few federal laws authorized funding to states and local agencies for identification, prevention, or remediation of elder abuse. Currently, the EJA authorizes funding in several areas, including grants to enhance the provision of APS by state and local agencies, as well as grants to support Long-Term Care Ombudsman Programs and funds to develop best practices to improve investigations of elder abuse that are reported in long-term care facilities. Although the EJA is now law, no funds have been appropriated to implement its provisions. Given the grave economic outlook for state and locally-funded APS agencies amid increasing service requests, a strong federal investment is needed in order to successfully move forward with the promise of the EJA.

Administration. All fifty states and the District of Columbia have statues that authorize and regulate the provision of services in cases of elder abuse. These statutes set up systems for reporting and investigating suspected elder abuse and for delivering services to victims. These laws vary widely from state to state, including on such characteristics as eligibility, the definition of abuse, reporting requirements, and investigation procedures. For example, eligibility for APS services is typically based on a statutorily defined disability, vulnerability or impairment, not solely on the age of the adult. Some state APS laws only apply to vulnerable citizens who are living alone or with family what is called "domestic abuse," while others go further and protect individuals who live in nursing homes and other long-term care facilities in instances of "institutional abuse." The ABA Commission on Law and Aging has developed detailed charts on threshold eligibility criteria for adult protective services, including a comparison chart of criteria by state and an age-specific comparison chart.

In addition to these regulations, approximately 15 states have separate statutes that address abuse, neglect, and exploitation of residents of long-term care facilities and other settings. The ABA Commission on Law and Aging has compiled a list of such statutes, titled Adult Protective Services, Institutional Abuse and Long Term Care Ombudsman Program Laws: Citations by State.

NASUAD Recommendations

Currently, the only federal requirements for state oversight and monitoring of assisted living facilities exist in the context of Section 1915(c) HCBS waivers and under the new Section 1915(i) and related quality assurance requirements. Significantly, Medicaid licensed units comprise only a small portion of the marketplace and no federal guidance exists for the oversight and monitoring for private pay assisted living, which makes up the majority of assisted living. At the state level, all states differ in their assisted living regulations, and the variation in state oversight is tremendous. To aid states in linking state licensure and survey agency roles and responsibilities more cohesively with Medicaid HCBS waivers, APS, and Long-Term Care Ombudsman efforts, NASUAD suggests the development of a

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federal template framework for an Assisted Living Bill of Rights and an Assisted Living Disclosure Statement, as well as increased funding for options counseling and resident advocacy services. Educating people about their assisted living options, rights in assisted living facilities, and resources to aid them when problems arise is critical. Accordingly, NASUAD respectfully supports:

Federal guidance on standard requirements for a Resident's Bill of Rights and Disclosure Statement. Building on the 2003 Senate Special Committee on Aging Assisted Living Work Group recommendations, federal guidance on a framework for a Resident Bill of Rights and Disclosure Statement is needed. The only minimum federal expectations or requirements for state oversight and monitoring of assisted living are in the context of Section 1915(c) waivers and under the new Section 1915(i) and related quality assurance requirements. In a 2007 study commissioned by the DHHS Assistant Secretary for Planning and Evaluation, researchers found that about 21 states have requirements for Resident's Rights, while requirements for Disclosure Statements are included in virtually all states, but the content varies considerably. A federal framework for a Resident's Bill of Rights and Disclosure Statement, along with a suggested tool for states to ensure compliance, would help to standardize this need among assisted living residences nationwide and offer all prospective assisted living residents a consistent format for comparing assisted living options.

Increased federal funding and for options counseling, including such counseling services delivered by I&R staff and ADRCs. This is necessary in order to educate potential residents on their rights, options, and long-term affordability of both public and private assisted living residences, as well as their options if spend down to Medicaid occurs. Additionally, potential residents, particularly individuals and families of low to middle income who could quickly exhaust their resources and turn to Medicaid, need objective, third-party assistance with understanding their assisted living options, including what they can afford and for how long. Options counseling could be extremely helpful to this population, but additional federal dollars are needed, as states currently do not have the funding to meet such demand.

Increased federal funding for state programs that provide resident advocacy services, including Adult Protective Services and State Long-Term Care Ombudsman. More resources for APS and State Long-Term Care Ombudsman services would also be helpful, since private sector assisted living is only subject to state licensure and not Medicaid-financed assisted living oversight. Through a regular presence in assisted living facilities, the ombudsman program provides both a quality monitoring system and a voice through which residents can address individual concerns about quality of care and quality of life. A stronger federal investment in APS and ombudsmen would allow these initiatives to leverage their existing authorized access to assisted living facilities and better protect residents through friendly visits, as well as random, surprise inspections, during which they would have the opportunity to determine if there is any evidence of patient neglect or abuse. Additionally, the ombudsman program is strategically positioned to provide Medicaid waiver programs with valuable information about the quality of care in these facilities, and increased funding could allow State Long-Term Care Ombudsmen to

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supplement the work of state licensure agencies, which generally survey assisted living facilities only once per year unless a complaint is submitted.

Full Funding for the Elder Justice Act. As more consumers age and require a wide array of services, including assisted living, there will also be a need for further protection and advocacy for those who are most vulnerable. In addition to the state and local ombudsman, adequate funding needs to be provided to improve the quality, quantity and accessibility of information and resources regarding long-term care, including assisted living. The Elder Justice Act provides for various safeguards and protections, but does not provide a dedicated funding stream to carry out the duties it assigns. Without federal appropriations and guidance for these important provisions, many of the enhancements outlined in the Elder Justice Act will not be implemented.

Broad Federal Definition. A federal definition based on the 2003 core principles of assisted living (i.e. efforts to support the autonomy, choice, privacy and dignity of residents) rather than a definition that includes specific housing elements (i.e. private bathroom, kitchen and lockable door to single-occupancy room) is needed. There is tremendous variation among state assisted living definitions, therefore any federal definition must be broad enough to address the array of state models, including housing with services, small assisted living facilities structured similarly to Adult Foster care, as well as larger settings. Components of the definition should address autonomy, choice, privacy, and dignity of residents.

Thank you again, Senator Kohl, Senator Corker, and Senator Nelson, for your leadership on these important issues and for the invitation to testify here today. I welcome your questions and comments, and I look forward to continuing to work together to improve the quality of life for older adults and individuals with disabilities, in whatever place they call home.

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United States Senate
Special Committee on Aging
Washington, DC 20510-6400

October 27, 2011

Honorable Chairman and members of the committee:

I respectfully submit to you the following statement with hope you can take action and strengthen the laws to protect our senior citizens living in Assisted Living Facilities.

My mother, Aurora Navas, was 85 years old when she accidentally died due to negligence at an assisted living facility in Miami, Florida. She was a hard working woman who always put her family first. Along with being a hard worker, she had a strong fear of water. She was terrified of pools, beaches, rivers and any body of water. Later in life she also grew afraid of darkness.

After she became ill with the terrible disease, Alzheimer, she was placed in an assisted living facility in Miami, Florida, where my sister lived and could visit her on a regular basis. I lived in Tampa at the time and my brother in Northwest Florida (Pan Handle).

The first time I visited my mother at the facility I wanted to be sure of a few things. I wanted to make sure she was being attended to properly, I was looking at the cleanliness of the facility, and especially how the staff treated its residents. Upon entering the facility I noticed a camera that was located above the kitchen entrance and was able to capture most of the facility's interior movement. The camera covered the main entrance, the hallway into the bedrooms, the kitchen, the living room, and the television area. I noticed a safety fence which prohibited the residents from entering the kitchen area. At a glance, I noticed that the doors were not locked. When I inquired about this, the staff told me that this was policy due to the local fire codes and that the double handles on the doors served as a safety feature since one handle turned in one direction and the other turned opposite. Near the end of my visit I walked towards the back of the property and noticed that the property was lakefront. The facility had a chain link fence surrounding it with multiple gates, which the staff told me it prevented the residents from going out. Finally, I noticed that the property next door had a dog that barked at anyone who got close the fence which added a little sense of security.

Unfortunately, on Sunday, January 27th 2008, in the very early hours of the morning, I received a disturbing phone call that changed my life forever. My sister had awoken me in a panic telling me there had been a terrible accident at the facility and that our beloved mother had passed away. Still in shock, I did not want to believe her and thought I must have been having a nightmare. I quickly rushed to the facility to see for myself and was immediately shocked by the presence of Police and crime scene tape. It was at this moment where my nightmare became reality.

I remember that cold Sunday morning very clearly, it was a terribly humid and cold night to the extent we were wearing heavy jackets and had to sit in the car with the heater on. Once the police had completed removing my mother's body and preliminary investigation was completed, we were approached by the detective and he took us into the entry way sitting area of the facility. He explained he was the lead detective on the case and proceeded to inform us of what he had found. He indicated mom had walked out of the facility and that she had drowned in the lake. He also told us the gate to the kitchen was open, one of mom's slippers was found in the kitchen and the other by the lake. The side door alarm had not been set properly; apparently the person on duty had fallen asleep and did not hear anything. The gates to the lake did not have locks to secure them. He indicated there was clear negligence because this could have been prevented.

The officer also indicated the investigation would continue until all facts, autopsy and police reports were completed and we could call him if we had any questions.
He proceeded to ask us for our contact information and gave us his business card. He expressed his condolences and told us we could leave since there was nothing else we could do.

As it turned out we were never contacted by anyone to tell us what was concluded as a result of the investigation. We had to hire a lawyer and through him we managed to get copies of the reports.

In reading the reports, it only raised more questions and contradictions which have never been answered:

My mother was always cold and she would never walk around without her slippers;
One of her slippers was found in the kitchen the other by the lake.

She was extremely scared of the water to the point she would not go to the beach and get in the water.
Yet she walked out of the facility on a very cold night and drowned in the lake.

She would not go outside on such a cold damp and dark night without a coat;
Yet she was only wearing a night gown when they found her.

She needed assistance to go up or down steps or getting into vehicles;
Yet she managed to walk down the steps on the side of the facility, which had no railings, and avoided falling.

Why were no scratches or bruises found anywhere on her body?

Why was the first call made to the owner of the facility when attendant found she was missing instead of 911?

Why was no dirty water found in her lungs but clean water in her stomach?

She was found in sixteen inches (16") of water according to the police dive team report.

Why was the camera not functioning?

Why were the written statements to the police all written in English? The staff on duty did not speak English.

Why was this operator allowed to continue operating after numerous violations without being fined?

Where is AHCA?

Where is law enforcement and prosecution? After all, these are deaths caused by negligence.

The one agency (AHCA) responsible for the oversight of these facilities was and is nowhere in sight. To my knowledge, they never even looked into my mother's death. I have received more information from the Miami Herald investigative team than from any government agency. Where is the connectivity between all the different agencies? How does the police notify States Attorney's office when deaths occur due to negligence, how is AHCA linked in?. From my perspective there is a clear disconnect which needs to be corrected as soon as possible. AHCA needs to rigorously enforce the laws governing ALFs and if they can't do it then we need to look at other ways to get it done, perhaps even incorporating AHCA into an existing agency.

If the laws are not strong enough then we are dependent on our legislatures to pass stronger laws which are enforceable so that our seniors are protected from these careless operators. If these operators continue to go unpunished it will only get worse as these unscrupulous people get reach on the backs of our seniors and tax payers.

I was appalled to learn the law only requires the operators of these facilities to carry an insurance policy of twenty five thousand dollars ($25,000) yet small contractors are required to carry two hundred and fifty thousand ($250,000) at a minimum. How absurd can this be? An Air Conditioning contractor has to carry a much larger policy then an ALF operator that deal with people's lives everyday.

I commend the Miami Herald's investigative team for their outstanding investigation and reporting bringing to light the abuse and neglect of our seniors in ALFs.

I would also like to thank this honorable committee for taking steps to preventing these terrible tragedies from occurring in the future and which most likely are occurring in every State were ALFs are operating.

Respectfully submitted,
Alfredo M Navas

United States Senate, Special Committee on Aging

Ensuring Quality and Oversight in Assisted Living

November 2, 2011

Testimony of Stephen J Maag J.D., Director of Residential Communities, LeadingAge

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.

Assisted Living: Fulfilling the Promise

Testimony before the Senate Special Committee on Aging
November 2, 2011

Robert Jenkens, Director
THE GREEN HOUSE® Project
NCB Capital Impact
www.ncbcapitalimpact.org

I. Introduction

Thank you Senator Nelson, Chairman Kohl, Ranking Member Corker, and other members of the Committee for the opportunity to share my thoughts on sustaining high quality affordable assisted living. I am Robert Jenkens. I currently direct The Green House Project, a partnership between NCB Capital Impact, The Robert Wood Johnson Foundation, Dr. Bill Thomas, and the pioneering states and providers that have joined with us.

The Green House Project assists nursing home and assisted living providers to implement a radically different approach to long-term care, one that truly operationalizes the founding values of the assisted living movement – autonomy, dignity, and privacy. Prior to The Green House Project, I directed the Coming Home Program. The Coming Home Program was also a partnership between NCB Capital Impact and The Robert Wood Johnson Foundation. Coming Home assisted nine states - Alaska, Arkansas, Florida, Iowa, Maine, Massachusetts, Vermont, Washington, and Wisconsin – to implement policies and programs to support the creation of high quality affordable assisted living for Medicaid-eligible individuals who cannot remain at home.

Coming Home worked with its state partners to implement or refine Medicaid waiver, regulatory, and housing finance programs essential to the creation and sustainability of high quality and affordable assisted living projects. The successful approaches and tools created by these states delivered 42 affordable apartment-style assisted living demonstrations. The policy, program, and financing tools created under Coming Home continue to assist in the development of new projects today.

Through the Coming Home Program and The Green House Project we have learned just how good assisted living can be. It can deliver on the promise of high quality resident-directed care combined with meaningful control, privacy, dignity, and better direct care jobs - all in a model affordable to Medicaid-eligible individuals. For more information about The Green House Project see www.thegreenhouseproject.org. For more information on the Coming Home Program see www.ncbcapitalimpact.org.

II. Observations

So how do we square the successes I have seen created through committed public/private partnership with the horrific stories bravely brought to light by the Miami Herald? How can we think about these opposites and use the successes to inform us on how to prevent abuses without stifling the innovation necessary to respond to evolving needs, preferences, and resource limitations? Four observations from

my experiences with Coming Home and The Green House Project may help illuminate a path to the solution we need.

First, we must ask if the providers responsible for these terrible events are the exception or the norm. As the Miami Herald found, the incidents of willful and significant abuse and neglect represent a small fraction of the providers operating in Florida. This is good news because it means that the majority of organizations that are providing quality services can be part of the solution.

Second, we should note that in many cases, the existing state complaint and review process was not followed or enforced despite repeated warning signs and formal complaints. The Miami Herald coverage suggests that if these complaints had been appropriately pursued, some of the worst outcomes may have been avoided. While the lack of enforcement in these cases is troubling, it means that elements of a solution may already be in place.

Third, we know from this example of regulatory failure and similar failures in other states, that financial and political pressures do not always allow the soundest state level quality assurance systems to be formulated or funded. This limits their performance. Just as we have learned from the nursing home experience, when Federal dollars are involved the Federal government has an appropriate role in establishing and holding states accountable for meaningful quality assurance practices. This is an area where, with some additional creative thinking, we can foster significant improvement.

Forth and finally, it is important to note that assisted living quality is not a Federal/state versus provider problem. The providers and trade associations I work with daily are united in their calls for cases of abuse and neglect to be punished swiftly and fully. They are motivated by their personal missions to improve the lives of people who need care and their business interests which are hurt severely when rogue providers are tolerated. This is important because it means that interests are largely aligned between consumers, regulators, and providers and that a creative solution likely exists.

III. Recommendations

So, what should be done? Do we need more state action? If so, what kind? Is there a different Federal role needed and, if so, what should that role be? From more than 20 years of experience in bridging policy to practice in long-term care, I can say yes to each of these questions. We do need more state action and an enhanced Federal role is required. For some of you in the room today, just voicing these beliefs causes deep concern. This is especially true in light of current economic pressures and the potential cost of new regulations. It is also a concern due to the potential impact of additional regulations on the continued innovation necessary to address rapidly evolving consumer preferences.

However, enhanced government involvement at the state and federal levels needn't cause concern. I believe strongly that the goals of quality enforcement and innovation are not mutually exclusive and, if created in partnership with advocates and providers, do not need to add costs or stifle innovation. In fact, I think they are necessary compliments and that we already have the overall state/federal regulatory framework in place that we need. The current framework provides the correct structure to balance appropriate minimum process and outcome standards, accountability, and creativity. We simply need to refine and bolster the framework in certain areas to allow it to fulfill its intended purpose. While these needed refinements are significant, they do not have to upset the Federal/state balance.

My first recommendation is targeted at refining the balance between state flexibility and accountability for minimum standards and outcomes. Currently, the Federal Medicaid waiver approval process allows states to propose the quality standards and monitoring system that work best for their goals and resources. While this is the essentially the right place to start, clear Federal expectations based on successful practices and outcomes should form the foundation of any state proposal. It is not enough, in my opinion, to defer to a state's judgment entirely. In fact, my experience in both Coming Home and The Green House Project points to the benefit that many state staff and legislators see in having clear Federal guidelines for the review of proposed state quality assurance processes, standards, and outcomes – guidelines that help them resist approaches that they are not confident in.

To create appropriate guidelines for quality assurance, standards that make sense to advocates, consumers, and providers, the Centers for Medicare and Medicaid Services (CMS) should be asked to develop these guidelines through an inclusive stakeholder initiative. An element of the quality assurance discussion should be on how to determine what minimum reimbursement rates are required for quality outcomes. This stakeholder initiative could be modeled on the successful Assisted Living Workgroup (ALW) formed in response to this Committee's 2001 challenge to the industry to "develop recommendations designed to ensure more consistent quality in assisted living" or the more recent 2011 efforts of the successor organization, the Center For Excellence in Assisted Living's (CEAL). Building on the processes and recommendations from the ALW and CEAL, and with the assistance of a team of CMS advisors who are experienced in assisted living issues, guidelines could be developed and refined over the next 6 months. At the direction of Congress, these guidelines could form the firm basis on which CMS evaluates and approves states' quality assurance proposals.

My second recommendation is targeted at accountability. The severity and duration of the quality crisis uncovered by the Miami Herald provides evidence that the CMS oversight role in waiver programs is not yet sufficient. We know this is not because CMS staff do not care enough, but rather because they lack the tools and resources to effectively monitor and enforce waiver performance. Rather than the regular Minimum Data Set monitoring and federal "look behind" surveys conducted by CMS for nursing home services, CMS monitoring of waiver quality assurance is based on complaints, and data self-reported by states annually and at waiver renewal. The CMS central and regional Medicaid offices do not have staff or a structure to perform verification of state quality assurance for home and community-based waiver services in the way that Congress has provided for survey oversight of inpatient facilities.

While we do not want to impose the often burdensome Federal nursing home approach to assisted living providers, the workgroup brought together to develop waiver quality-assurance guidelines could also make recommendations on a more effective Federal monitoring and enforcement role, including intermediate sanctions. Congress could then evaluate these recommendations, direct CMS to implement selected enhancements, and provide additional funding as required to assure that beneficiaries and this essential industry does not suffer unnecessarily due to lax oversight.

Thank you again for the opportunity to testify today. I look forward to answering your questions.

The Miami Herald
Posted on Sat, Jul. 16, 2011

Assisted-living facility blamed in woman's drowning death

By Michael Sallah, Rob Barry and Carol Marbin Miller
msallah@miamiherald.com

Kenny Malone

Isabel Lopez with her dogs Ron and Nina at Isabel Adult Care II in Miami.

When Aurora Navas' lifeless body was pulled from the dark waters, her caretakers promptly reported her death to the state: Resident with dementia drowned after losing her way back to the assisted-living facility.

The blame was squarely on the 85-year-old woman and her dementia, wrote the facility owner. "All precautions were taken."

But three years later, state investigators say a tragic sequence of breakdowns in the Miami-Dade home — including the failures of her caretakers — proved far more deadly than the elderly woman's dementia.

State agents say the conditions were ripe for disaster: a sleeping caretaker, broken surveillance cameras, door alarms not working and an unlocked gate.

"The responsibility and culpability was with the home to ensure the safety mechanisms were in place," said Mark Riordan, a spokesman for the Department of Children & Families.

Navas was among dozens of frail and elderly people who died at the hands of their caretakers in ALFs across Florida in the past decade without any investigation by the lead regulator overseeing the homes, the Agency for Health Care Administration, The Miami Herald found.

For the past three years, the state's only record of her demise was from the home's owner, Isabel Lopez, who blamed the elderly woman's "senile dementia."

But after a profile of her death in The Miami Herald revealed discrepancies in the home's version of events, another state agency, DCF, opened an investigation in May.

Their findings would directly contradict the details the home sent to the state three years ago — a series of events never questioned by regulators.

"No one ever contacted us from the time my mom died," said Alfredo Navas, 59, the youngest of her three children. "It's obvious AHCA is not doing the job."

Navas' move to the ranch-style home near a small lake in southeast Miami-Dade came just a year after the Cuban native was diagnosed with Alzheimer's disease.

Her children never planned to place her in an ALF, but as the disease took hold, their options began to narrow. Eventually, daughter Annie Navas, 61, decided to place her aging mother in Isabel Adult Care III, a home licensed to care for people with mental disabilities.

WRENCHING CHOICE

For Alfredo Navas, leaving his mother in the care of strangers "was heartbreaking," he said. "She would beg me to take her out of there. She did not want to be there."

But after several trips to the home, he said he was comforted by the cleanliness of the facility, and the surveillance camera on the wall. "That made me feel safer, that perhaps everything is recorded."

What followed, however, was a sweeping collapse of safety precautions that would ultimately lead to his mother's death, records shows.

Two weeks after celebrating her 85th birthday at the home — complete with a Mariachi band — family members received a call that would sear into their memories: Aurora Navas' body was found floating in the pond just steps from the home's back yard.

By the time Alfredo Navas arrived, Miami-Dade police had already roped off the lake, emergency lights illuminating the trees.

The revelation that his mother had drowned stunned him and other family members, he said, because she would never go near water. "She couldn't swim," he said. "Mom was petrified of the water."

Within hours, family members learned that everything that could have gone wrong went wrong in the moments before her death.

One of the caretakers in the home had fallen asleep.

The surveillance cameras that had given family members peace of mind were not plugged in.

The door alarms — designed to sound a piercing wail when residents try to leave — were improperly set.

The back gate — the only protection between the property and the lake — was left unlocked.

By the time a caretaker, Flor de Maria Palomino, looked into Navas' room at 3:55 a.m., the elderly woman was gone.

"The safeguards you thought were in place weren't in place," said Alfredo Navas, whose family reached a confidential settlement with the home last year. "Why did they allow this to happen?"

Within minutes, the 69-year-old Palomino found the back door ajar and soon spotted Navas' body floating face-down in the shallow water, a lone blue slipper on the grass nearby.

BETRAYED TRUST

Though the breakdowns in the home were quickly discovered — including the sleeping caretaker, unlocked gate and failed alarm — the details would remain buried for the next three years.

Because Miami-Dade police did not report the death to the abuse hotline — a requirement under state law — the only record sent to the state was from the home itself, which claimed it had done nothing wrong.

Home owner Isabel Lopez wrote AHCA in a report two weeks later that "all procedures were followed," including "door alarms, proper door locks, and a fenced backyard... there are no other restrictions that we could put into place. All precautions were taken so that an occurrence like this would not happen."

That version stood unchallenged because AHCA — empowered under law to investigate all such cases — declined to look into the death, records show.

For family members, the lack of a state investigation was infuriating. "You trust your lawmakers and the agencies designed to oversee [ALFs], because that's why we pay them," said Alfredo Navas. "They're getting paid by the government, our taxes, and they're not doing their job."

Isabel Lopez declined to comment.

Riordan said DCF launched an investigation after the drowning was reported in The Herald in May. Police and rescue workers, he said, should have alerted the agency during the death investigation three years ago. "It was a mandated call," he said.

Miami-Dade police spokesman Javier Baez said he could not determine Friday whether a call to DCF was made in the case.

SON'S REGRETS

Shelisha Coleman, a spokeswoman for AHCA, said the agency does not comment on death investigations, but confirmed that inspectors were at the home on Friday.

For Alfredo Navas, the visit is too late." They ought to shut [AHCA] down and transfer [their duties] to a department that can do the job," he said. "People are dying."

Just a month before Navas' death, AHCA found two female residents at Isabel Adult Care had fallen and injured themselves — with both breaking bones and rushed to the hospital

— and the home had failed to report the incidents to regulators as required by law, records state.

Inspectors also found staff members who were not trained in caring for people with mental illness, as well as a resident who was being overcharged hundreds of dollars a month.

Annie Navas said the past three years have been frustrating because the state should have launched an investigation of the home after her mother's drowning. "I called the state attorney's office three times and never got a call back. I asked the police to re-investigate," she said, adding there was "no interest in re-opening" the case.

The most difficult challenge: coping with the fact that she placed her mother in an ALF that didn't protect her. "To this day, I have to live with it. It's not easy."

WLRN Miami Herald reporter Kenny Malone and Miami Herald staff writer Deborah Acosta contributed to this report.

During the November 2 Aging hearing on Assistive Living Facilities, Barbara Edwards from CMS agreed to identify some states with best practices in quality improvement.

As promised, here's a list of some important quality initiatives underway in the states. Note that this is not intended to be an exhaustive listing of all quality initiatives in states.

Alaska

- *Populations Served: Individuals with Intellectual Disabilities/Developmental Disabilities, Physical Disabilities, Aged, and children with Complex Health Needs.*
- *Alaska has overall, an excellent quality monitoring system.*

Connecticut

- *Populations Served: Individuals with Intellectual Disabilities/Developmental Disabilities (Assisted Living is a service in one waiver)*
- *Connecticut has a robust incident management system, mortality review process, provider monitoring and collection of consumer outcomes.*

New Mexico:

- *Populations Served: Individuals with Intellectual Disabilities/Developmental Disabilities, Aged, Medically Fragile Children*
- *New Mexico has a cross population/cross-waiver critical incident management system which is making headway in the state.*

Massachusetts

- *Populations Served: Individuals with Intellectual Disabilities/Developmental Disabilities Critical Incident*
- *Massachusetts has a management system, a mortality review process, and provider monitoring.*

Ohio

- *Populations Served: Individuals with Intellectual Disabilities/Developmental Disabilities*
- *Ohio has a critical incident management system, provider monitoring, and a mortality review process.*

South Dakota

- *Populations Served: Individuals with Intellectual Disabilities/Developmental Disabilities, Quadriplegics*
- *South Dakota has an automated quality data collection system that integrates provider monitoring/reporting.*

American Seniors Housing Association

Statement for the Record of the American Seniors Housing Association

United States Senate Special Committee on Aging

Hearing on Limited Mental Health Facilities and Assisted Living in Florida
November 2, 2011

The American Seniors Housing Association (ASHA) is pleased to have this opportunity to submit comments for the record related to the U.S. Senate Special Committee on Aging hearing on Assisted Living issues in the state of Florida scheduled for November 2, 2011. ASHA was created in 1991 and represents approximately 350 leading companies that own, manage, or finance approximately 600,000 units of seniors housing in the U.S. and Canada, comprising senior apartments, independent living, assisted living, memory care, and continuing care retirement communities. ASHA represents both for-profit and not-for-profit companies that develop, own, and operate "purpose-built" seniors housing communities.[1]

It is our understanding that this hearing was prompted by a Miami Herald investigative series relating to assisted living facilities in Florida published earlier this year. The Miami Herald series pinpointed specific abuses occurring in 22 assisted living facilities (ALFs) in the state of Florida over the last decade and identified a number of deficient state regulatory responses to these cases. These tragic reports are highly disturbing, not only to ALF residents and their families, but also to all the assisted living providers in Florida and throughout the United States – the overwhelming majority of which provide daily exemplary quality care and service to our nation's frail seniors.

As disturbing as these examples of neglect and abuse are, they represent a very small fraction of the hundreds of thousands of assisted living residents who have been very competently and compassionately served in nearly 2,000 assisted living communities throughout Florida during the time period covered in the investigative series. Many of the cases cited occurred several years ago and at least one as far back as 2002. Several of the communities have since closed, have surrendered their license, or are under new ownership.

Yet, it is critical that the state of Florida officials with responsibility for protecting ALF residents take corrective action. The vast majority of cases cited by the Miami Herald

[1] Purpose-built assisted living communities include private, lockable apartment-style living units that typically include separate sleeping and living areas, an individual bathroom, and kitchenette with a microwave and/or mini-refrigerator; fully carpeted living and dining spaces; attractive artwork; residential furnishings; and special purpose rooms such as a library and exercise room.

relate to a failure to follow existing legal requirements applicable to ALFs, including the slow response of regulators when abuses were discovered. Despite repeated violations and, in some cases, severe and egregious acts of abuse and neglect that Agency for Health Care Administration (AHCA) did not act to close down these operations promptly.

Also of very serious concern is the fact that Florida has not taken steps to recognize that Limited Mental Health (LMH) facilities are very different from assisted living.[2] From the outset, assisted living has always been a regulatory model focused on care for seniors who need assistance with activities of daily living due to frailty or cognitive decline. Nationwide, assisted living residents are overwhelmingly frail seniors in their mid to late 80's (primarily widowed women) with physical care needs. Those residents generally pay privately for their services. The individuals served in LMH facilities in Florida are distinctly different from assisted living residents in the rest of country, and thus many of the abuse and neglect issues highlighted in the investigative series associated with these facilities are unique to Florida's regulatory model and a far cry from the standards of excellence commonly found in traditional assisted living settings, including most ALFs for seniors in the state of Florida.

Roughly half of the 22 ALFs cited in the investigative series were licensed Limited Mental Health facilities. These settings serve individuals diagnosed with mental health disorders, such as schizophrenia and bi-polar disorders. These types of settings serve a mentally ill population that are predominantly young men and never married or divorced individuals with extremely low incomes.[3] We have serious concerns about the appropriateness of placing individuals with mental illness in assisted living, and in particular, housing frail seniors in an environment with residents exhibiting behavioral problems that are substantially younger in age with very different needs, both physically and socially.

Critically, Florida is virtually alone in including mental health facilities in its assisted living licensure category. Moreover, LMH facilities in Florida are currently not subject to additional mandatory monitoring inspections outside of the required biennial inspection, despite the fact that they are caring for an especially vulnerable population. Florida also does not require any additional education and experience for administrators of LMH facilities. We believe that Florida's LMH facilities should be subject to a similar inspection process that Florida requires of other facilities that hold specialty licenses such as Limited Nursing Services (LNS) and Extended Congregate Care (ECC) facilities.

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[2] To qualify for placement in a Limited Mental Health facility, an individual must receive social security disability income due to a mental disorder or supplemental security income due to a mental disorder and receive optional state supplementation which is a cash assistance program to supplement a person's income to help pay for costs in an ALF.

[3]Deborah Street, PhD., Stephanie Burge, PhD., Jill Quadagno, Ph.D., *The Effect of Licensure Type on Facilities and Resident Composition of Florida Assisted Living Facilities*, The Gerontologist, Volume 49, November 2, 2009.

Since the Miami Herald series was first published, we are pleased that Florida Governor Rick Scott has implemented a number of substantive measures to examine fully the regulations and system of agency oversight deficiency to protect residents from abuse and neglect in the future. Several recommendations call for a number of significant regulatory changes and legislative proposals to streamline the regulatory process of ALFs and foster more efficient reporting of complaints.[4] In the interim, the Florida Senate professional staff has recommended that the state Legislature take immediate action to designate a specific agency as the lead agency to coordinate all complaints and other problems related to ALFs. Additionally, the state legislature held hearings to examine the circumstances surrounding the issues raised by the Miami Herald series, and several legislators intend to introduce legislation in the next session to address many of the recommendations stemming from these hearings and Governor Scott's specially appointed task force.

The evolution of effective and rigorous oversight of assisted living across all states has emerged over the past two decades as a result of a highly collaborative effort among key stakeholders at the state and local level.[5] Unlike federal nursing home regulations which evolved from a top down "one size, fits all" approach, assisted living regulations evolved at the state and local level and reflect the voice of the customer (i.e. the residents, family members and other key stakeholders). Indeed, the concept of assisted living has flourished precisely because it is *not* a "cookie cutter" federal regulatory model. Strong private pay demand for assisted living has been largely driven by the quality of life experienced in assisted living and the emphasis placed on service innovation and customer satisfaction.[6] Occupancy levels nationally consistently remain high averaging 90 percent, and in many markets of the country, exceed 90 percent.

The guiding philosophy of assisted living embraced by consumers across this country is to provide person-centered care in a residential setting that allows seniors freedom of choice, independence and the opportunity to live with dignity and respect. Virtually every state regulatory framework embodies this guiding philosophy and states have responded to increasing consumer demand to allow assisted living communities to serve

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[4] The Florida Senate professional staff issued a comprehensive set of actionable recommendations in September 2011 to address a myriad of regulatory deficiencies identified in the series; Governor Rick Scott appointed a task force comprised of state policymakers, industry representatives, and consumer advocacy groups to develop recommendations for legislative action. The report is tentatively scheduled for release in November 2011; and the Florida Agency for Health Care Administration (AHCA) which is responsible for regulatory oversight of ALFs has assessed more than $125,000 in fines to 44 ALFs for their failure to comply with state regulations, taken administrative action against 46 ALFs during May 2011, imposed a moratorium on admission to two ALFs, issued an emergency suspension order, and denied an application for license renewal to an ALF with a history of deficiencies. (Source: The Florida Senate Interim Report, September 2011)

[5] ASHA has a long history of collaboration with state policymakers in promoting responsible state regulations and strong oversight and enforcement, and publishes a yearly state summary of state regulatory changes which are posted on its website, www.seniorshousing.org.

[6] It is estimated that private pay occupancy in assisted living averages 90% nationwide.

residents with higher acuity needs. Provisions in regulations have been strengthened in areas related to staffing, training, medication administration, Alzheimer's care, life safety, resident rights, resident assessment standards, development of service plans, and disclosure requirements.[7] These areas have been a particular focus among surveyors. Several states utilize a number of highly effective survey strategies, including providing technical assistance and follow-up to specific problems identified during the survey process; timely follow-up on complaints; having clear lines of communication and definition of duties for survey staff; developing clear enforcement procedures that are well understood by surveyors meeting with providers to discuss issues; providing training; conducting follow-up visits; and maintaining a consumer perspective that focuses on improving care, not just punishing past failures.

All 50 states and District of Columbia post links to their licensing regulations and statutes. States also post information to assist consumers and family members to determine whether residential care can meet their needs and compare service offerings at various communities. In addition to standardized state consumer disclosure forms, there are a number of national and state trade associations that make available consumer checklist guides with detailed questions to ask when considering assisted living. Assisted living consumer checklists are posted on several national trade association websites, including the American Seniors Housing Association (www.seniorshousing.org) the National Center for Assisted Living (www.ncal.org), the Assisted Living Federation of America (www.alfa.org), LeadingAge (www.leadingage.org) as well as consumer advocacy websites, including the Center for Excellence in Assisted Living (www.theceal.org) and AARP (www.aarp.org).

The assisted living industry recognizes that maintaining the quality of its services is important to the overall well-being of residents. Best practices are promoted and dissemination of information about evolving standards is a priority of assisted living trade associations. Best practices cover a wide range of services, including dementia care, medication administration, dietary service, resident assessments, activities, hospice care, etc.[8] The vast majority of assisted living providers offer exceptional housing and services to the nation's seniors, and consumer satisfaction is overwhelmingly positive. The

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[7] In 2010, at least 18 states reported making statutory, regulatory or policy changes impacting assisted living. At least six states made major changes, including ID, KY, OR, PA, SC, and TX. Between 2004 and 2007, 21 states revised their regulations and 12 states reported current activity to revised regulations. In 2009, at least 22 states reported making statutory, regulatory or policy changes and at least eight states made major statutory or regulatory changes or overhauled their rules (Sources: *Assisted Living and Continuing Care Retirement Community State Regulatory Handbook 2011*, ASHA, LeadingAge; *Assisted Living State Regulatory Review*, March 2011, National Center for Assisted Living)

[8] The Center for Excellence in Assisted Living (CEAL) is a non-profit collaborative of 11 national organizations formed in 2004 to maintain a national clearinghouse for information on quality and effective practices in assisted living. Other organizations that promote best practices in assisted living include the American Seniors Housing Association (www.seniorshousing.org); Assisted Living Federation of America (www.alfa.org); the National Center for Assisted Living (www.ncal.org); LeadingAge (www.leadingage.org); and the Alzheimer's Association (www.alz.org).

industry, for its part, has worked diligently with key stakeholder groups in assisting states to improve quality in assisted living.

We support the reviews under way in Florida, and believe that Florida remains best equipped to deal with their unique regulatory issues relating to assisted living. We are confident that the state will take all necessary corrective regulatory measures to improve the state's ability to monitor quality and safety in ALFs and ensure the well-being of assisted living residents and appreciate the opportunity to comment on important quality issues related to assisted living.

David S. Schless
President

United States Senate
Special Committee on Aging

Ensuring Quality and Oversight in Assisted Living

November 2, 2011

Statement by Assisted Living Consumer Alliance, the National Consumer Voice for Quality Long-Term Care, National Senior Citizens Law Center, and the Long-Term Care Community Coalition

I. Introduction

The Assisted Living Consumer Alliance (ALCA) is a national collaboration of groups and individuals who have joined together to promote and preserve choice, safety, and legal rights and protections for assisted living consumers. ALCA members serve as a resource for information and advocacy, and work collaboratively with consumers, health care professionals and others to examine assisted living policies and to engage stakeholders and policymakers on important assisted living issues.

The National Consumer Voice for Quality Long-Term Care (The Consumer Voice), formerly NCCNHR, was formed in 1975 because of public concern about substandard care in nursing homes. The Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. It provides information and leadership on federal and state regulatory and legislative policy development and models and strategies to improve care and life for residents of long-term care facilities.

The National Senior Citizens Law Center (NSCLC) works to promote the independence and well-being of low income elderly and persons with disabilities through advocacy, litigation, and the education and counseling of local advocates.

The Long-Term Care Community Coalition (LTCCC) was formed as an ad hoc coalition in the 1970s on the heels of nursing home scandals in New York State. In 1982, because of a recognized need for a persistent watchdog and advocate for long-term care residents, LTCCC became a permanent coalition. It became incorporated in 1989. In over two decades LTCCC has brought together many diverse groups whose work led to successful improvements in the federal and state public health codes, historically significant regulatory reform, a landmark assisted living law, and upgrades in surveillance activities and enforcement systems. LTCCC's coalition membership includes consumer, civic and professional organizations, and individuals from all parts of New York State.

We commend the Special Committee on Aging for addressing this important topic. We are familiar with the circumstances detailed in the *Miami Herald* articles, and believe that the problems documented in those articles are attributable to systemic inadequacies in the definition and regulation of assisted living. Congress and the Centers for Medicare and Medicaid Services (CMS) can play an important role in addressing these inadequacies and, in doing so, protecting the health and well-being of the hundreds of thousands of Americans who currently reside in assisted living facilities.

II. The Federal Role in Assisted Living

Assisted living is licensed at the state level. There is great variability in assisted living facilities from state to state, and also from facility to facility within the same state. The state-to-state variability results from the different definitions and regulations used by each state. For example, Alabama has "assisted living facilities," California has "residential care facilities for the elderly," and Minnesota has "housing with services establishments." The different terminology is only the tip of the iceberg, as the relevant state laws differ greatly in such important regulatory aspects as the type of care that can be provided, the training that staff members must receive, and the extent that nurses and other health care professionals participate in the care.

The variability *within* a state results from the fact that, in many states, the state regulations defer greatly to the service providers. To a certain extent, the provider has discretion to set its own standards, as the standards to be followed are to be set by the admission agreement and/or disclosure statements, both of which are drafted by providers. In these states, the state law may purport to be flexible to accommodate consumers' needs, but it is our experience that regulatory flexibility generally redounds to the benefit of providers, not consumers. For example, we are familiar with eviction rules, and the flexibility in many states' eviction standards allow a facility to evict a resident with increased care needs even though the resident's care needs could be met under the facility's license.[1]

[1] National Senior Citizens Law Center, Critical Issues in Assisted Living 43-48 (2005).

The federal government is involved in assisted living principally through the Medicaid program's payment for assisted living services. This payment for services (not for housing) is generally made through a Medicaid Home and Community-Based Services (HCBS) waiver, although it may also be made under Medicaid payment for personal care services, or through the relatively new state option of providing home and community-based services through a Medicaid state plan[2].

Importantly, HCBS waivers and the other Medicaid payment mechanisms are not limited to assisted living settings. In fact, the vast majority of Medicaid beneficiaries receive HCBS or comparable services in their own homes. Thus, HCBS waiver applications and similar documents contain little or no specific detail about assisted living services. In their waiver applications, states are required to provide assurances to the federal government that quality of care is adequately protected, but these assurances for assisted living services generally consist of a pro forma citation of the state's assisted living licensing rules. Notably, these licensing rules may assume an assisted living population with relatively limited care needs, even though HCBS waiver beneficiaries by definition require nursing home services or an equivalent elevated level of care.

Although states are required in HCBS waiver applications to list a quality management strategy, we have found that this requirement offers little benefit to consumers. In our experience, such quality management strategies are based on data available only to states and local agencies. The federal government is given assurances by the state that the system is working as designed, but the federal government has no ability or inclination to look behind the state's assurances. Consumers have even less access to this process. In any case, such data analysis is generally useless to consumers, as they need concrete regulatory standards to set minimums in such important areas as the type of care that must be made available, and the training that must be provided to direct-care staff. Data analysis does not give consumers or providers adequate guidance as to how care should be provided.

It should be noted that CMS this spring released proposed regulations that would set standards for when an assisted living facility can be considered a home and community-based setting for purposes of Medicaid funding.[3] We strongly support CMS's efforts in this area, and submitted extensive comments on how the proposed regulations could be revised to most effectively achieve their purpose. Those comments are available on the ALCA website, www.assistedlivingconsumers.org.

III. The Long-Term Care Ombudsman Program and Assisted Living

Long-term care ombudsmen are advocates for individuals living in nursing homes, board and care, and assisted living facilities. They resolve individual complaints made by or on behalf of residents; as well as work for systems change at the local, state, and national levels. Started as a demonstration project in 1972, the Long-Term Care Ombudsman Program is authorized under

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[2] More information on this Medicaid funding is available in a series of reports written by the National Senior Citizens Law Center. *See* Medicaid Payment for Assisted Living, www.medicaidalseries.org

[3] *See* 76 Fed. Reg. 21311 (April 15, 2011).

the Older Americans Act and exists in every state, the District of Columbia, Puerto Rico, and Guam. Program data for FY 2010[4] indicate that ombudsman services were provided by the 53 State LTC Ombudsmen, 1,167 FTE program staff, and 8,813 trained and certified volunteers.

In working to resolve complaints or advocate on behalf of residents, long-term care ombudsmen take direction from the residents themselves. Their goal is to resolve an issue to the satisfaction of the resident, rather than as a means of determining or fulfilling compliance with state regulations or standards. As such, ombudsmen work collaboratively with other state agencies including adult protective services and the state agency that licenses and oversees assisted living facilities, but do not have authority to impose fines or other remedies, or to take other corrective action against a facility.

Ombudsmen have the ability to raise awareness of problems or concerns at a facility before they become serious issues. Yet many programs are faced with inadequate resources to have a regular presence in facilities. According to the FY 2010 National Ombudsman Reporting System (NORS) data, only 39% of board and care/assisted living facilities received regular (quarterly) visits from long-term care ombudsmen, as compared with 74% of nursing homes. More than 51,000 complaints regarding care and services in board and care and assisted living facilities were handled by long-term care ombudsman in FY 2010.

As it addresses individual and systemic concerns about quality and services, the long-term care ombudsman program provides a means of monitoring quality in a long-term care facility. Adequate funding for the program would increase ombudsman presence in facilities, thus allowing increased quality monitoring and resident advocacy and support.

IV. Recommendations

In light of the discussion above, the undersigned organizations make the following recommendations:

A. Establishment of federal standards for assisted living residents

As Medicaid beneficiaries and monies are increasingly shifted from nursing homes to assisted living facilities and other HCBS settings, it is entirely appropriate that Congress and CMS establish some standards on what type of services can be considered assisted living services for the purposes of Medicaid reimbursement. Reasonable minimum standards are vital for the safety and well-being of Medicaid-eligible assisted living residents, and also for the efficacy of the Medicaid program itself. In these days of budgetary limitations, neither the federal nor state governments should be paying for "assisted living services" without defining those services adequately.

Any standards should be based on clear and successful practices and outcomes and developed with a broad range of stakeholders. Additionally, federal standards should include a

[4] National Ombudsman Reporting System Data FY 2010

system through which CMS would monitor the quality assurances of the waiver programs, as well as the standards adopted.

Standards should include provisions and protections generally available under Medicaid law, including protections from discrimination and impoverishment. Standards should also address staffing levels, staff training, rights, such as protections from involuntary discharge in the event a facility withdraws from participation in Medicaid. Quality of care must be adequately safeguarded.

B. Standards for community character

Assuring that assisted living facilities are not institutional and reflect the characteristics of a home and community setting is essential. Overall, we support the spirit and intent of the proposed CMS regulation on HCBS waivers and believe it is a strong step forward in ensuring the home and community based nature of these facilities.

However, there are several critical elements missing from the proposed regulation that are necessary for an assisted living facility to be truly community-based. The living unit or room should be a specific physical space owned or rented by the person receiving services. Living units should include bathrooms, kitchenettes and lockable doors. Since lockable doors and kitchenettes may be problematic for individuals with dementia or comparable cognitive limitations, there should a waiver of these requirements if the presence of the kitchenettes or lockable door is determined by a person-centered plan to be a danger to the individual. Facilities with a capacity of six or fewer persons (not including staff) could be exempted from this requirement.

Furthermore, because privacy is such a key hallmark of home and community- based living, shared bedrooms should only be allowed for spouses and partners. Currently in many facilities certified to accept Medicaid HCBS reimbursement, unrelated recipients share bedrooms because they are offered no real alternative. The resident "chooses" to share but it is not really a choice since there are no alternatives. This type of forced shared occupancy is contrary to the principles of assisted living.

C. Federal oversight of assisted living

CMS should strengthen its oversight and enforcement of quality of care and quality of life in assisted living facilities that receive Medicaid funding. Currently CMS relies on assurances and data from the states as evidence of quality, yet does not investigate to determine the accuracy of what the state submits. As recommended above, federal standards should be applied and enforced. Also, CMS should be required to develop a method for evaluating both the assurances and data from a state and should conduct "look behinds" to make sure the states are providing the services and oversight they say they are. When this is not the case, CMS should be given the authority to impose intermediate sanctions rather than simply cutting off funding, and such intermediate sanctions should not include capping waiver enrollment, which penalizes beneficiaries.

Other federal government programs or agencies that provide monies to assisted living facilities, such as the Department of Housing and Urban Development, should also strengthen their oversight and enforcement. In addition, the Federal Trade Commission should enforce federal law that prohibits false advertising and unfair and deceptive trade practices, while federal law enforcement agencies should enforce civil rights laws and program requirements that protect the legal rights of assisted living resident and applicants. Such enforcement is critical both to protect residents' rights and safety, and to ensure that federal money is used properly.

D. Increased federal funding for advocacy services provided by the Long-Term Care Ombudsman Program

We also support additional funding for the Long-Term Care Ombudsman Program. Long-term care ombudsmen serve a vital role in promoting quality of care and quality of life for residents living in assisted living facilities. By providing a regular presence in assisted living facilities, ombudsmen empower and educate residents, provide information to staff, and address issues and concerns at both the individual as well as the systems level. Additional resources would increase ombudsman presence in assisted living facilities when they are most needed, now that we see increasing numbers of very frail, vulnerable, nursing home eligible people opting to live in this setting. As noted earlier, ombudsman presence also allows ombudsmen to raise awareness of problems before they become serious issues that result in harm to residents.

We appreciate the opportunity to submit the above comments for the record of this important hearing. Please direct questions to:

Eric Carlson, NSCLC Directing Attorney, ALCA President, ecarlson@nsclc.org; or Robyn Grant, The Consumer Voice, Director of Advocacy and Outreach, rgrant@theconsumervoice.org.

ALFA
Assisted Living Federation of America

www.alfa.org

"Ensuring Quality and Oversight in Assisted Living"

Hearing before the Senate Special Committee on Aging
November 2, 2011

Testimony for the Record
Submitted by Richard P. Grimes, President/CEO
Assisted Living Federation of America

Chairman Kohl, Ranking Member Corker and Members of the Committee:

On behalf of the Assisted Living Federation of America thank you for the opportunity to submit testimony for the hearing on *Ensuring Quality and Oversight in Assisted Living.*

The Assisted Living Federation of America (ALFA) is a national membership organization representing senior living providers and the residents and families they serve. ALFA's members are companies that operate *professionally-managed, consumer-driven communities for seniors* inclusive of independent living, assisted living and memory care. ALFA's member companies provide a resident-centered *alternative* to institutional forms of care (such as that provided by hospitals and nursing homes) for the 1,000,000+ frail elderly seniors in need.

Central to our work are core principles embracing the belief that seniors should have *choice* about where and how they want to live, have optimal *independence* in whatever option they choose, are treated with *dignity* and *respect*, and have a superior *quality of life*. ALFA's member companies apply these principles through their service to seniors every day.

ALFA member companies are not only committed to providing quality care and quality of life for their residents, but to providing an atmosphere that fosters independence, dignity and respect for the residents, family members, and employees of their senior living communities. ALFA members affirm, that prospective residents and their families are fully informed to make their best decisions about living arrangements and other services. Specifically, they pledge to:

- provide detailed information about the living environment, any amenities and or services offered and the fees for such services.
- provide a written summary of the community's policies and procedures including reasons that may require the resident to move to another setting,
- provide and explain the dispute and complaint resolution process.
- provide information about the resident's rights, as defined by state law or regulation as well as contact information for the local/state long term care ombudsman and the state regulatory agency if appropriate.
- honor all written commitments made to residents and their families.

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In addition, ALFA member companies must ensure that *quality improvement* is a critical part of their ongoing work and they must focus on improvement efforts in those areas deemed most important by their customers and by their team members. To these ends, they are pledged to obtaining feedback from families, residents and team members on a regular basis.

ALFA's member companies have professionally managed senior living communities with committed caregivers and a culture of caring. They have corporate and community policies, procedures, and training programs that, in practice, exceed regulatory requirements under most conditions. They have decades of experience developing best practices—and they share "lessons learned" with each other to improve their service to seniors.

Evidence of our ability to provide choice, independence, dignity and quality of life can be found in independent surveys showing high levels (90%+) of resident and family satisfaction.

Service to Frail Elderly Seniors

With regard to the assisted living aspect of the senior living sector, our members (and others) often serve frail elderly seniors who need assistance with activities of daily living such as bathing, dressing, eating, or toileting. These are individuals who do not need the 24/7 nursing care provided by skilled nursing facilities.

For these individuals, assisted living is a *home*—not an institution—and the choice, independence, dignity and quality of life of those who call assisted living home are extremely important to the residents and their families. Most residents (82%) of professionally managed assisted living communities pay out of their own pockets from their own private resources.

Today, there are many assisted living options available at different price points: large and small; urban and rural; traditional and contemporary; hi-rise and single level. The move to an assisted living community is preceded by much thought and consideration by the potential resident and/or family members. Over a period of weeks or months, they research the available options, make multiple visits to different communities, and have in-depth discussions with community representatives.

And, once the move is made, there is much incentive for the senior living community to provide quality service and quality care. They know that if they don't, their residents can "vote with their feet". That is, they can move down the street to a competing senior living community which is also working hard to provide quality service and quality care for all their residents.

Assisted Living is Regulated in the States

Frail elderly seniors are among our most vulnerable citizens and they must be protected from those who would neglect or abuse them. To this end, all 50 states have oversight of assisted living; all 50 states regulate assisted living.

State oversight of assisted living allows customized laws and regulations to reflect the needs of seniors who reside in the state. The diversity of our states does not allow for a one-size-fits-all model as the expectations and needs of seniors in one state are often very different from the expectations and needs of seniors in another state. Thus, to meet each of their citizen's needs, each individual state has built regulatory frameworks that are reflective of the unique features, culture and customs of the state.

While there are excellent laws, regulations and regulators in every state, ALFA and our ALFA State Affiliates and Chapters work with the states to ensure they are continuously evaluated to meet the changing needs of assisted living residents while protecting them from neglect and abuse. We support strong state laws and regulations for all who may provide assisted living services.

- We believe that the state should conduct annual unannounced survey inspections in communities that provide assisted living services with flexibility to offer longer survey cycles or abbreviated survey visits for communities who have demonstrated consistent compliance.

- We believe that communities providing assisted living services should be appropriately sanctioned if found to be providing less than quality care and quality of life to its residents. This may mean citing deficiencies, fines, bans on admission and other corrective action. In the most egregious cases, it may mean closing a community.

- We believe states should embrace the *resident-centered* philosophy of senior living that has produced a vibrant and responsive business serving seniors and their families. Regulations should promote and protect choice, independence, dignity and quality of life; and not dictate to seniors and their families' public policy that is paternalistic and ageist.

The Challenge of Enforcement

From time-to-time, there are calls for "more" regulation of assisted living. This is usually tied to high profile incidents of neglect or abuse in communities licensed to provide assisted living that are not professionally managed. In almost all cases, a community licensed to provide assisted living services has not been in compliance with existing laws and regulations and the state did not enforce the existing laws and regulation.

Unfortunately, as states cut budgets, state regulatory agencies are increasingly compromised. Without the staff and resources to do their jobs, frail elderly seniors and other vulnerable populations are put at increasing risk.

In Florida, for example, neglect and abuse was exposed by the Miami Herald in a series of articles last May. It is evident that the state regulatory agency was not enforcing the regulations for a number of group homes for the mentally ill.

Promulgating even more regulation on top of existing regulation would not have prevented these incidents. They could have been prevented by simply enforcing the existing law.

Models of Effective Enforcement

As states face challenging financial times, they are seeking ways to ensure all their vulnerable citizens are protected. ALFA has reached out to the Association of Health Facility Survey Agencies (an association of state regulators) with ideas and offer of support.

Further, we've shared some excellent models of effective enforcement. Faced with cutbacks, for example, the state of Wisconsin developed an effective model that is aggressive against communities with persistent or serious non –compliance while at the same time recognizing the exemplary providers. By reallocating their resources, there has been increased provider/regulator collaboration, a decrease in the number of poor providers, and increased quality of care for the seniors in Wisconsin.

We hope one outcome of today's hearing of the Senate Special Committee on Aging is that attention will be drawn to the lack of resources in the states. States must adequately fund those regulatory agencies charged with overseeing the administration of laws and regulations intended to protect its seniors and other vulnerable populations. In turn, those funds must be directed in such a way that seniors (and other vulnerable populations such as the mentally ill or developmentally disabled) and their families have confidence that they are receiving the care and quality of life they deserve.

In service to frail elderly seniors in each of the 50 states, ALFA is committed to doing what we can to support the state regulatory agencies in carrying out their mandates. We share with the U.S. Senate Special Committee on Aging the goal of ensuring that all of America's vulnerable citizens, especially frail seniors, enjoy quality of life free from harm and in an environment that offers choice, dignity and independence.

Families for Better Care

• *November 2, 2011* •

Comments to the United States Senate Special Committee on Aging

"Ensuring Quality and Oversight in Assisted Living"

On behalf of the thousands of residents who live in assisted living facilities across America, Families for Better Care applauds the U.S. Senate Special Committee on Aging for their commitment to ensuring residents who live in assisted living facilities receive quality care. Additionally, special thanks to Senator Nelson and his leadership in championing the rights of elderly and mentally disabled citizens.

Not too long ago, Florida's assisted living model was *the* long-term care ideal for other states to emulate. Marketed to consumers as the "new alternative" for America's aging baby boomer population, "assisted living" was intended to offer consumers a flexible alternative to the arcane, institutional environment of nursing homes. These residential care settings were fashioned to be a place where our parents and grandparents could live independently and receive assistance with routine daily activities.

But an investigative series by the *Miami Herald* has exposed gaping fractures within this once heralded enterprise.

Lax oversight, ambiguous or non-existent resident safeguards, and politically compromised ombudsman programs have contributed to a growing pandemic of resident neglect and abuse nationally. But some operators attest that these egregious issues are "just a Florida problem."

Yes, these are serious problems in Florida, but the industry's critique is far from the truth.

Florida has historically been the staging ground for enacting progressive legislation to protect seniors. Other states monitor Florida as a case study to determine "what works, and what doesn't work." So it only goes to show, that if problems are happening in Florida, equal, or worst, cruelties are happening to residents elsewhere.

But herein lies the problem; government agencies, providers, advocates, and consumers have little idea about the magnitude of these issues because of varying state laws that present an unclear picture of assisted living facility quality. Data are circumspect because of the lack of clear guidance by the federal government.

And with the addition of Medicaid waiver initiatives and nursing home diversion programs, the assisted living facility landscape is being dramatically altered.

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Frailer, more vulnerable residents who require complex medical services are admitted into assisted living facilities whose staff are grossly undertrained and inadequately supervised. The influx of residents requiring more care has blurred the lines between assisted living facilities and nursing homes to unintentionally create "unregulated, mini-nursing homes." These "pseudo-assisted living" are stretching the limits of state laws that govern the assisted living facility industry and are putting residents at risk for harm.

The establishment of federal regulations would ensure regulatory consistency from state-to-state and provide comfort to consumers to know that their "long-term care purchase," in which they will be entrusting their very lives, is not a lemon. With the enactment of these regulations, Medicare.gov could be updated with assisted living reports to provide real-time regulatory data so consumers, and regulators, can adequately gauge assisted living facility quality.

Additionally, the Center for Medicare and Medicaid Services should be provided the authority to shut down those assisted living facilities with chronic problems when state regulatory agencies fail to take appropriate action on behalf of residents. This added measure would prevent resident abuse and neglect.

But the lynchpin to making all of this work for the residents is an autonomous Long-Term Care Ombudsman Program.

The Office of State Long-Term Care Ombudsman, authorized under the federal Older American Act, is *the* watchdog of the long-term care industry, mandated to advocate exclusively on behalf of residents.

A core tenant of the program is systems advocacy.

While the Older Americans Act provides some latitude for ombudsmen to initiate systems advocacy through a variety of mechanisms (e.g., commenting on proposed laws or rules, facilitating public comment, and developing resident and family councils) the Act falls short in protecting the ombudsmen.

Ombudsmen nationwide have, at one time or another, been forced to compromise on their systemic advocacy due to internal and external conflicts or willful interference. Politically charged entanglements and intimidation have crippled the ombudsman program throughout its history.

In fact, an unprecedented compliance review of Florida's Long-Term Care Ombudsman Program by the Administration on Aging released in early September, uncovered federal violations by state officials, resulting in a *"grave blow"* that will *"affect the confidence that residents have in the program."*

Although the Act establishes that willful interference with or retaliation against an ombudsman are unlawful, enforcement of these provisions are relegated to states to define. In Florida, these violations constitute criminal acts, punishable by a $500 fine and a second-degree misdemeanor, hardly a deterrent from any insidious political impropriety.

The Older Americans Act must be amended to clearly define and ensure ombudsmen autonomy. Furthermore, any interference with an ombudsman should be a federal crime and warrant an investigation by the Department of Justice.

With well-defined federal oversight, assisted living facilities can cease from becoming boarding homes for elders and warehouses for residents with mental health challenges and live up to the person-centered care model they were intended to be, providing residents and consumers with a safer long-term care option.

If you have any comments or questions, please feel free to contact me by phone at 850.491.2198 or by email at brian@familiesforbettercare.com.

Yours in service,

Brian Lee,
Executive Director

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RICK SCOTT
GOVERNOR

Better Health Care for all Floridians

ELIZABETH DUDEK
SECRETARY

Response and Supplemental Materials provided by the Florida Agency for Health Care Administration based on the testimony presented at the November 2, 2011 Senate Special Committee on Aging

Submitted electronically to: Hearings_Aging@aging.senate.gov

The Agency's Role in Health Care Regulation

The Agency for Health Care Administration (the Agency) has and continues to take our job as a lead health care regulator seriously. Our primary consideration is for the safety of residents. The Agency is dependent upon information reported by consumers, advocates and others who may have concerns or observe problems in an assisted living facility (ALF) or any health care facility regulated by the Agency.

The Agency's goal is to respond to concerns raised about any regulated provider. When the Miami Herald "Neglected to Death" series was published in May, the Agency immediately responded to their accusations that we knew about certain incidents and failed to take action. We immediately increased communication with other state agencies involved in assisted living facilities, although we have always worked collaboratively with our sister agencies, recent efforts have focused attention on facilities of concern so we can collectively evaluate the full array of regulatory tools available to address these concerns. The Agency was aware of many of the issues identified in the series and imposed sanctions, including emergency moratoria prohibiting new admissions and other sanctions. Some facilities ultimately changed ownership or closed.

There were some incidents where complaints were not filed with the Agency. This underscores the importance of reporting problems for investigation and is why so much of our attention in recent months has focused on outreach to our partner agencies, consumers and other health care providers who visit assisted living facilities.

Increased Outreach Activities Results in Increased Reporting

Over the past several months, the Agency has conducted significant outreach activities to ensure our partners know when and how to report concerns, including other health care providers who serve assisted living residents such as home health agencies. An "Assisted

Living Facility Observations" document was created and disseminated to help those visiting assisted living facilities know what activities should raise questions and be reported; it is provided in an appendix to this response. The Agency has asked our partner agencies including the Department of Elder Affairs and the Long Term Care Ombudsman, the Agency for Persons with Disabilities, the Attorney General's office, the Department of Children and Families Abuse Protection and Mental Health staff, and others to bring issues to our attention so we have information to build the strongest case possible for any necessary regulatory actions.

In addition, there have been interagency assisted living facility staffing meetings (1-2 per month since May) to review the status of facilities for which the Agency has recently taken or has pending administrative actions (moratoria, licensure suspensions, revocations) and to discuss other agency concerns. Attended by all entities involved in the regulation, reimbursement or placement of individuals into assisted living facilities, the meetings ensure that the state is taking an integrated approach in the handling of poor performing providers. The staffing meetings allow the team to identify poor performing providers, to assure that any severe licensure actions are coordinated with Medicaid actions (which may include suspension of payments or termination of the provider number), and to coordinate with other agencies to address Medicaid waiver programs or other state involvement. These meetings also serve to facilitate the timeliness and appropriateness of any resident relocations that may result.

In addition to our efforts, the heightened attention brought about by legislative and media interest has contributed to increased public awareness. As a result, the number of complaints reported against ALFs has increased by more than 25% in recent months, and the Agency has investigated accordingly. Our response to complaints is swift; within one day for concerns of serious resident harm, and an average investigation time of 22 days for all assisted living complaints. It is important to make sure consumers, families, and advocates know when and how to contact the Agency with concerns. The Agency's consumer complaint line is available at 1-888-419-3456 or online at http://ahca.myflorida.com/Contact/call_center.shtml.

Regulatory Activity and Pressure Results in Closing of Underperforming Facilities

Currently there are 2,962 assisted living facilities in Florida, an increase of 26% since 2006. Annually, the Agency conducts over 6,000 visits to these facilities through licensure and complaint inspections. Each year, over 10,000 citations are issued for failure to meet licensure requirements—some minor and some serious. Florida law authorizes fines and other sanctions for serious deficiencies or failure to correct minor deficiencies. Last year $776,238.44 in fines were imposed for violations; additional information about this is included the supplemental materials. The Agency has and continues to take serious action in cases of significant regulatory violations.

The Miami Herald articles cite a limited number of regulatory actions against Florida assisted living facilities over the last 5 years; however, regulatory action has been taken against a significant number of facilities. In addition to licensure sanctions to fine, deny and revoke licenses, more than 200 assisted living facilities have closed during litigation or because of legal

or regulatory pressure. These actions often stem from information received from complaints reported by those aware of problems. The chart below displays emergency actions to ban admissions (moratoria) or suspend a license, successful legal actions to deny or revoke an existing facility, and closures with a history or current legal action pending.

	FY 06/07	FY 07/08	FY 08/09	FY 09/10	FY 10/11	FY 11/12 to date	Total
Moratoria	7	7	5	4	7	4	34
Suspensions	3	0	2	1	2	0	8
Revocations	3	5	4	12	7	2	33
Denials of Active Licenses	8	6	11	7	5	4	41
Closed or Failed to Renew*	38	34	37	40	46	12	207

** Closed or failed to renew a license with pending legal cases or history of licensure legal actions.*

In addition to our partner outreach, we have moved quickly to finalize changes to several inspection processes that have been under development for the past year, including:

- an enhanced resident-centered inspection process increasing the focus on resident and family feedback, onsite observations, and expanding the investigation based on identified concerns,
- an abbreviated inspection process for facilities with a successful regulatory and Ombudsman history over the past four years,
- additional staff training and focused violation guidance, and
- establishment of an Assisted Living Enforcement Team to support investigations, coordination, enforcement, and compliance in the program.

These changes enable greater consistency and expertize in assisted living oversight and an enhanced focus on poor performing facilities.

We continue to work with the Centers for Medicare and Medicaid Services to address any questions about Medicaid participation in assisted living facilities and have hosted onsite reviews of our monitoring programs.

As stated by Dr. Polivka during your hearing, Governor Scott has convened an Assisted Living Workgroup which held its final meeting November 7-8, 2011. Their work has been very valuable and identified several opportunities for improvements. Their recommendations are being finalized and will likely result in changes to Florida assisted living laws. Workgroup materials and final recommendations will be available on the Agency's website at www.ahca.myflorida.com. We will continue to work with all interested partners to address issues as identified and remain committed to resident safety and well-being in all our programs.

Additional Information Provided as Supplemental Materials

Supplemental materials provided as appendices are:

1. Information for 24 facilities mentioned in the first two months of the Miami Herald articles about assisted living facilities in Florida,
2. "Assisted Living Facility Observations" document, and
3. The September 2011 draft whitepaper called "Assisted Living Facilities in Florida," which was created by the Agency for Health Care Administration and has been used as a resource document for Governor Scott's Assisted Living Workgroup.

Thank you for the opportunity to provide information about Florida's oversight of assisted living facilities.

Sincerely,

Sonya Kidd

for Elizabeth Dudek
Secretary

APPENDIX 1

Supplemental Materials

The Agency was able to ascertain the following about the 24 facilities that were mentioned during the first two months of articles printed by the Miami Herald:

- 3 of the facilities changed ownership either due to the incident or shortly after the incident described:
  - Briarwood Manor
  - Sunshine Acres (License currently Suspended, pending Revocation and Denial)
  - Arlington House (subsequently closed)

- 2 of the facilities were placed under a moratorium and also fined:
  - All American ALF
  - Southern Oaks

- 10 of the facilities were fined or cited for the incident mentioned:
  - Hillandale
  - Emeritus at Becket Lake/Becket Lake Lodge
  - Edwinola Manor
  - Heart of Florida ALF/Hampton Court
  - Living Legends/Willow Bay at Deerfield Beach
  - A Better Place/Escondido Palms/Beehive Manor
  - Munne Center (subsequently closed)
  - Crystal Gem Manor
  - Dunedin/Rosalee Manor
  - Meadows of Kendall/The Gardens of Kendall, Inc.

- 2 of the facilities either closed as a result of the mentioned incident:
  - K & K Adult Care Center
  - Emeritus at Crossing Point

- 7 of the instances described at facilities were not brought to the attention of the Agency—the individual, family member, caretaker or other concerned person never brought the incident to the attention of the Agency as a complaint:
  - Isabelle Adult Day Care III
  - Sterling House of West Melbourne/Alterra Claire Bridge (Clare Bridge of West Melbourne)
  - Williamsburg Landing
  - Mapleway
  - Nueva Vida
  - Forest Oaks
  - Park of the Palms

APPENDIX 2

Assisted Living Facility Observations

The following are concerns or inappropriate care that, if observed in an assisted living facility, should result in contact with the appropriate agency as listed. Prior to your visit you should review the Agency for Health Care Administration licensure website at www.floridahealthfinder.com to verify license status, prior visits and violations, sanctions and any current emergency actions.

The following concerns may be reported to the Agency for Health Care Administration Complaint Office at 1-888-419-3456 or online at ahca.myflorida.com/Complaint.

1. **Proper licensure.** Is a valid license posted in the facility visible to those who enter? If not, verify licensure at www.floridahealthfinder.com. If the facility is not licensed, but appears to be operating as an ALF, report possible unlicensed activity.

2. **Mechanical lifting equipment.** Mechanical lifting devices such as Hoyer Lifts are prohibited in ALFs. Residents who need mechanical lifting devices to get out of bed or chairs are not appropriate for an ALF.

3. **Sufficient food.** Based on the menu, is there enough food to prepare (including snacks)?

4. **Medication administration.** Does any resident indicate they are not receiving their medication?

5. **Resident whereabouts/ safety.** Have any residents eloped (missing) and what is the response?

6. **Restraints.** Restraints are prohibited. Are restraints being used? Examples of restraints: Buckle or Velcro seat belt in the wheelchair that resident cannot release, Geriatric Chairs with lap trays and, the use of sheets tied to a chair to support resident. Family request is not justification for the use of restraints. Only half- bed rails are allowed with a physician's order every 6 months. **An ALF resident who is also on hospice care can have full bed rails if the health care provider and interdisciplinary plan identifies that the resident needs them.**

7. **Building Safety.** Obvious and urgent safety hazards related to the building such as unstable construction, fire alarms, or building safety devices (locking mechanisms) should be made to local building officials. Obvious and urgent safety hazards unrelated to the building may be reported to AHCA.

8. **Hygiene.** Is the resident's hygiene being neglected? Is the resident dirty with dirty or wet clothing? Are odors present? Although residents have the opportunity and are

encouraged to perform personal hygiene, staff should recognize the need. Clothing should be clean and in good repair, however, a resident cannot be forced to wash or change clothes.

9. **Resident Rights.** Do residents state that their grievances go unanswered or they feel their rights have been violated? Ask residents if they are aware of the facilities' policy and procedures. Some express concern of no-mail delivery on Saturday, mail being received opened and of not being provided with the required 45 day notice of discharge.

10. **Bed bound.** Are any residents bed-bound? Residents may be bedbound in an ALF for a limited number of days. At no time should a resident be bedbound for more than 14 consecutive days.

11. **Nursing Services.** Are any residents receiving 24 hour nursing services? Residents may not be admitted to any ALF if they require 24-hour nursing supervision. If a resident, after admissions, requires 24 hour nursing supervision, the services may be provided in accordance with the continued residency requirements found in rule.

12. **Peg Tubes.** A resident with a Peg Tube does not meet admission criteria unless the Peg Tube is maintained by the resident. If a resident's health deteriorates and peg tube is required, the resident may remain in the assisted living facility provided the resident is terminally ill and on hospice. The peg tube must be maintained by licensed staff and facilitated by hospice as specified in the interdisciplinary care plan. However, facilities with an LNS or ECC license may provide these services through an interdisciplinary plan with a hospice provider.

13. **Pressure sores.** A resident cannot remain in any ALF with stage 3 or 4 pressure sores. If a resident is admitted with a stage 2 pressure sore, the ALF must have:

- Limited Nursing Services (LNS) or Extended Congregate Care (ECC) license and provide the appropriate nursing care
- The ALF must employ or contract with a nurse to provide the care
- The resident must contract with a home health agency for nursing care

If there is no improvement in 30 days, the resident must be discharged.

14. **Oral, nasopharyngeal, or tracheotomy suctioning.** The resident cannot require suctioning in a standard or LNS facility unless the resident is under the care of hospice. ECC facilities may provide tracheotomy suctioning, but all other suctioning is prohibited unless the resident is under the care of hospice.

Filing a complaint with the Agency for Health Care Administration:

- To file your complaint, call (888) 419-3456, or complete the Health Care Facility Complaint Form at: ahca.myflorida.com/Complaint
- Your complaint can be filed anonymously, however if you wish to know the results of your complaint, you should be prepared to give your name, address and telephone number. This information will allow our surveyors to contact you should they need additional information or clarification.
- Be prepared to give detailed information such as patient/resident names, dates, times of events and where the event happened or is currently happening.
- After filing your complaint, it is immediately forwarded electronically to our Complaint Administration Unit for review and priority assignment.
- If after assessment, it is determined that AHCA has the regulatory authority to conduct an inspection based on your concerns, the complaint will be scheduled for inspection. If the information given leads us to believe that one or more residents are in any immediate danger, the field office will conduct an inspection within two business days.
- If after assessment the Complaint Administration Unit determines that AHCA will not conduct an inspection at this time, you will be notified in writing of this determination and why. If another agency has authority to look into your concerns, you will be notified that we have referred your information to that agency. Due to the Health Insurance Portability and Accountability Act (HIPAA), we would have to remove all identifying information from your complaint, which limits the receiving department's ability to effectively evaluate the information. We will give you the referral information and ask that you forward your concerns to that department, so the integrity of the complaint remains intact.
- Although an inspection may not be conducted, your general concerns are kept on file and considered during future inspections.
- If an inspection is conducted, you will be notified in writing of the outcome.

Filing a complaint with the Department of Children and Families Florida Abuse Hotline:

- Florida Abuse Hotline 1-800-962-2873; TDD (Telephone Device for the Deaf): 1-800-453-5145 www.dcf.state.fl.us/programs/abuse
- Contact the Florida Abuse Hotline immediately if the residents are at risk of serious injury or death. The Florida Abuse Hotline is available 24 hours a day, 7 days a week.

- The Florida Abuse Hotline will accept a report when a vulnerable adult is believed to have been abused or neglected by a caregiver in Florida, or suffering from the ill effects of neglect by self and is need of service, or exploited by any person who stands in a position of trust or confidence, or any person who knows or should know that a vulnerable adult lacks capacity to consent and who obtains or uses, or endeavors to obtain or use, their funds, assets or property.

- WEB REPORTING: Web reporting should not be used for situations requiring immediate attention. Please contact the Hotline's toll free reporting number if you believe a child or vulnerable adult is at imminent risk of harm. To make a report via the Florida Abuse Hotline's web reporting option, please gather all of your information in advance and click the following link to access the web reporting option: www.dcf.state.fl.us/abuse/report/. Reports may also be made by FAX using forms provided.

- NOTIFICATION OF REPORT: Telephone reporters will always be told prior to concluding your conversation, whether the information provided has been accepted as a report.

This Assisted Living Facility Observations document is available on the web at: ahca.myflorida.com/assistedliving.

Assisted Living Facilities in Florida

Assisted living facilities (ALFs) began in Florida with the legislature's 1975 adoption of the Adult Congregate Living Facilities (ACLF) Act. Since that time, amendments to the ACLF Act created specialty licenses that expanded the list of allowed services beyond nursing services" (LNS). In 1989, "limited mental health services" (LMH) were authorized. In 1991, the legislature authorized ACLFs to provide "extended congregate care services" (ECC). In 1995, ACLFs were renamed "assisted living facilities" (ALF). In 2006, the regulation of ALFs was transferred from Chapter 400, F.S., to part I of Chapter 429, F.S., and named the Assisted Living Facilities Act.
Today, Florida Statute defines an *assisted living facility* as any building or residential facility that provides "housing, meals, and one or more personal services for a period exceeding 24 hours to one or more adults who are not relatives of the owner or administrator." When it created the Assisted Living Facilities Act in 2006, the Florida Legislature sought to promote the availability of services for elderly persons and adults with disabilities "in the least restrictive and most homelike environment, to encourage the development of facilities that promote the dignity, individuality, privacy, and decision-making ability of such persons."

ALF Services

Today, Florida ALFs range in size from one resident to several hundred and can include individual apartments or rooms that a resident shares with another person. Basic ALF services include:

- Housing, nutritional meals, and special diets
- Help with the activities of daily living (bathing, dressing, eating, walking)
- Giving medications (by a nurse employed at the facility or arranged by contract)
- Assisting residents to take their own medications
- Supervising residents
- Arranging for health care services
- Providing or arranging for transportation to health care services
- Health monitoring
- Respite care (temporary supervision providing relief to the primary caregiver)
- Social and leisure activities

Some ALFs arrange or directly provide these services to their residents. Others require the resident to arrange their own services as agreed upon in the contract between the resident and the facility. An ALF may employ or contract with a nurse to take vital signs (blood pressure, pulse, respiration, and temperature), manage pill organizers, give medications and keep nursing progress notes. A resident can also contract with a licensed home health care provider for nursing and other health care services, as long as the resident's needs do not exceed what is allowable in that assisted living facility or what is specified in the resident's contract with the assisted living facility.

If an ALF in Florida would like to provide any services beyond those allowed in the standard license, it must acquire a "specialty" license. These licenses allow the ALF to accept residents who need more advanced nursing or mental health care. The specialty licenses include:

Limited Nursing Services: A limited nursing services (LNS) specialty license enables an ALF to provide, directly or through contract, a select number of nursing services in addition to the personal services that are authorized by the standard license. The nursing services authorized to be provided under this license may only be provided as authorized by a licensed practitioner's order. A nursing assessment that describes the type, amount, duration, scope, and outcomes of services, and the general status of the resident's health, is required to be conducted at least monthly on each resident who receives a limited nursing service. An LNS licensee is subject to monitoring inspections by the AHCA or its agents at least twice a year.

An ALF with a limited nursing services license provides the basic services of an assisted living facility as well as additional nursing services. Some of the limited nursing services are:

- Nursing assessments
- Care and application of routine dressings
- Care of casts, braces, and splints
- Administration and regulation of portable oxygen
- Catheter, colostomy, and ileostomy care and maintenance
- Application of cold or heat treatments, passive range of motion exercises, ear and eye irrigations

Limited Mental Health: An ALF that serves three or more mentally ill or disabled residents must obtain a limited mental health (LMH) specialty license. For the purposes of assisted living licensure, a mental health resident is defined as an individual who receives social security disability income (SSDI) due to a mental disorder or supplemental security income (SSI) due to a mental disorder, and receives optional state supplementation (OSS). This definition is limited as there may be other assisted living facility residents with severe and persistent mental illness who have a case manger but do not meet this specific definition.

A limited mental health license must be obtained if an assisted living facility serves three or more mental health residents. The LMH license requires basic staff training in mental health issues and requires the ALF to

- ensure that the resident has a community living support plan,
- provide assistance to the resident in carrying out the plan, and
- maintain a cooperative agreement for handling emergency resident matters.

There may be residents with severe and persistent mental illness who have a Department of Community Affairs (DCF) case manager but do not otherwise meet the definition of a mentally ill ALF resident. Since the specialty license is only required if the ALF has three or more "mental health residents", a facility can serve one or two mental health residents without a Limited Mental Health license (no requirement for mental health training of staff or assistance with the community licensing support plan). Pursuant to 394.4574, F.S., the Department of Children and Families must assure that:

- A mental health resident has been assessed by a psychiatrist, clinical psychologist, clinical social worker, or psychiatric nurse to be appropriate to reside in an assisted living facility,
- A cooperative agreement to provide case management, as required in s. s. 429.075 F.S, is developed between the mental health care services provider and the administrator of the ALF-LMH,
- A case manager is assigned for each mental health resident,
- The community living support plan, as defined in s. 429.02 F.S. has been prepared by a mental health resident and a case manager in consultation with the administrator of the facility, and
- The ALF is provided with documentation that the individual meets the definition of a mental health resident.

Each DCF Circuit Administrator develops, with community input, annual plans that demonstrate how the district will ensure the provision of state-funded mental health and substance abuse treatment services to residents of ALF-LMH facilities.

Extended Congregate Care: An assisted living facility with an extended congregate care license provides the basic services of an assisted living facility as well as:

- Limited nursing services and assessments
- Total help with bathing, dressing, grooming and toileting
- Measurement and recording of vital signs and weight
- Dietary management, including special diets, monitoring nutrition and food and fluid intake
- Supervision of residents with dementia and cognitive impairments
- Rehabilitative services
- Escort services to medical appointments
- Educational programs to promote health and prevent illness

An ALF is required to perform and document a monthly assessment for residents who are receiving nursing services, including any substantial changes in the resident's status which may indicate the need for relocation to a nursing home, hospital or other specialized health care facility.

The ALF is required to notify a licensed physician within 30 days when a resident exhibits signs of dementia or cognitive impairment, or has a change of condition, in order to rule out the presence of an underlying physical condition that may be contributing to the dementia or impairment.
The owner or administrator of a facility is responsible for determining the appropriateness of admission to the facility and for determining the appropriateness of a resident's continuing stay in the facility.

The Comprehensive Assessment and Review for Long-Term Care Services (CARES) program performs the federally mandated function of conducting nursing home pre-admission screening and assessment for Medicaid long term care programs. Persons who are applying for Medicaid-funded nursing home care are assessed by a CARES nurse or social worker, with medical review by a physician prior to approval. One of the program's functions is to assist eligible Floridians in obtaining home and community services to avoid nursing home care. Another function is the continued education of the public, particularly health care providers, about less costly alternatives for long term care.

Medicaid reimbursement for assisted living services is limited to people who are eligible to participate in waiver programs or receive assistive care services. The Nursing Home Diversion Program is designed to provide home and community based services to older persons assessed as being frail, functionally impaired and at risk of nursing home placement. An array of long term care services, Medicaid-covered medical services and Medicare services are coordinated and delivered through managed care organizations (MCOs) contracted with the Department of Elder Affairs.
The facility is required to provide 45 days' notice of the need for relocation or termination of residency unless, for medical reasons, the resident is certified by a physician to require an emergency relocation to a facility providing a more skilled level of care, or the resident engages in a pattern of conduct that is harmful or offensive to other residents.

ALF Statistics

Since 2003, the number of Florida ALFs has grown by nearly a third (30.28%). In 2003, a Florida ALF was most likely to be mid-sized (25 beds or less) and serving a diverse resident population as indicated by the number of beds dedicated to extended congregate care (ECC) for medically complex residents , and the indigent as measured by participation in the Optional State Supplementation (OSS) program.

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	# of ALFs	# of Beds	# ALFs w ECC Beds	# ECC Beds	# ALFs w OSS Beds	# OSS Beds
2003	2,272	76,714	398	18,853	1,176	14,171
2004	2,275	74,788	346	17,967	1,179	14,100
2005	2,291	74,282	327	16,144	1,205	13,992
2006	2,340	74,317	312	15,316	1,206	13,881
2007	2,442	75,958	306	15,064	1,249	14,161
2008	2,643	77,338	302	16,124	1,367	14,665
2009	2,783	79,302	306	16,882	1,454	15,436
2010	2,850	81,027	308	16,976	1,505	15,709
2011	2,960	82,951	277	14,480	1,521	15,686

In 2011, Florida ALFs are increasingly small (the majority now house six or fewer beds) and serve an increasingly diverse population after increases in the number of LMH and OSS beds. The number of Florida ALFs serving the limited mental health population increased by over 80% from 2003 to 2011. The number of facilities with OSS beds increased by nearly 30% during the same time period.

The steady increase in the annual total of licensed ALFs (as shown above) understates the impact of new licensees each year. While Florida has had an average annual net increase of 86 new ALFs since 2003, the Agency has also approved an annual average of 125 changes of ALF ownership during the same period. Data gathered since 2009 also documents that an average of 125 ALFs have been failing to renew their licenses each year. This pattern is continuing based on year-to-date information for 2011. All of these factors result in more than a 10% turnover of newly licensed ALFs each year.

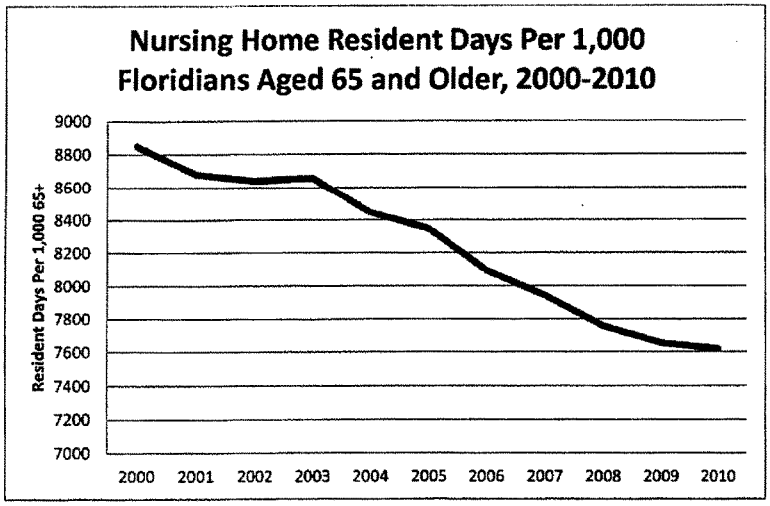
	% Incr. # ALFs	% Incr. # Beds	% of ALFs ≤ 6 Beds	% of ALFs ≤ 25 Beds	% ALFs w LMH Beds	% ALFs w ECC Beds	ECC Beds as % of Total	% ALFs w OSS Beds	OSS Beds as % of Total
2003			37%	65%	27%	18%	25%	52%	18%
2004	0%	-3%	38%	66%	33%	15%	24%	52%	19%
2005	1%	-1%	37%	68%	34%	14%	22%	53%	19%
2006	2%	0%	41%	67%	35%	13%	21%	52%	19%
2007	4%	2%	43%	67%	36%	13%	20%	51%	19%
2008	8%	2%	47%	69%	38%	11%	21%	52%	19%
2009	5%	3%	50%	70%	38%	11%	21%	52%	19%
2010	2%	2%	52%	73%	38%	11%	21%	53%	19%
2011	4%	2%	52%	72%	37%	9%	17%	51%	19%

ALF Residents

The original Florida ACLFs began as residential homes for elderly or developmentally disabled residents who needed limited assistance with daily tasks such as bathing, meals or medications. However, a detailed picture of current ALF residents is very difficult to create due to the lack of data. Assisted living's role as a less intensive residential alternative to skilled nursing facilities has been and continues to be based on assumptions about the resident population: they are those too frail to live alone but not yet in need of full-time skilled nursing care.

This attitude may be changing as the potential interest in resident protection grows. What is clear from existing sources is that the number of very small facilities is increasing rapidly, as is the mental health population. Both of these trends have major implications for assisted living facilities. Regulating a large facility of generally healthy seniors requires a different approach than regulating a five-bed facility serving primarily LMH residents.

We presume that Florida ALFs are also housing people who once would have been more likely to live in skilled nursing facilities. While there is no Florida data source that can specifically document this trend, it is widely assumed. One of the main reasons for the assumption is the decrease in nursing home utilization that has occurred since 2000. Though the statewide average percent occupancy in nursing homes has remained relatively constant between 85 and 88 percent, the state's elder population has been growing and aging, masking the actual decline in nursing home utilization. The following graphic illustrates the decline by showing a steady drop in statewide nursing home resident days per 1,000 Floridians aged 65 and older.



This drop occurred during a statewide moratorium on the addition of new nursing home beds. When the moratorium began in 2001, there was an expectation, based on the use rates of the 1990s, that Florida nursing homes would be overcrowded by now. The fact that overcrowding has not occurred while the elder population has been growing leads many to conclude that ALFs are housing more frail individuals with diverse and complicated medical issues.

ALF Regulation

The Agency for Health Care Administration currently licenses over 40,000 services and facilities including:

- Abortion Clinics
- Adult Day Care Centers
- Adult Family Care Homes
- Ambulatory Surgery Centers
- Assisted Living Facilities
- Birth Centers
- Clinical Laboratories
- Crisis Stabilization Units
- Health Care Service Pools
- Health Care Clinics
- Home Health Agencies
- Health Maintenance Organizations
- Home Medical Equipment Providers
- Homemaker Companion Organizations
- Homes for Special Services
- Hospices
- Hospitals
- Intermediate Care Facilities for the Developmentally Disabled
- Nurse Registries
- Skilled Nursing Facilities (Nursing Homes)
- Prescribed Pediatric Extended Care Centers
- Residential Treatment Facilities (Mental Health)
- Short Term Residential Treatment Facilities (Mental Health)
- Transitional Living Facilities

Agency licensure activities include processing initial, renewal and change of ownership applications; conducting licensure and complaint inspections; monitoring and citing violations; and sanctioning providers and facilities when serious or repeat violations are identified. The conduct of these duties the Agency each year processes approximately:

- 16,000 licensure applications
- 200,000 background screenings
- 8,000 complaints
- 21,000 inspections and investigations
- 1,900 financial reviews
- 160,000 consumer calls
- 2,300 public information requests

The goal of these activities is to assure compliance with the laws and regulations that safeguard Florida's health care consumers. However, when the regulations are violated, the law specifies when sanctions are imposed and requires the consideration of several factors prior to imposing a penalty. In 2010, Agency's Division of Health Quality Assurance imposed sanctions (by final order) including:

- 3,900 cases
- $5,728,778 in fines
- Denial of 94 provider applications
- Imposition of 14 emergency moratoria (suspend admissions)

Historically, few of the violations cited by the Agency result in patient or resident harm and most are corrected expeditiously. However, any licensee that refuses or fails to achieve regulatory compliance risks closure, license revocation, denial of the renewal license or denial of a change of ownership to a new operator.

The regulation of assisted living facilities is governed by licensure statutes and rules:

- Basic requirements that are shared with other regulated health care facilities are found in Chapter 408, Part II, Florida Statutes and Chapter 59A-35 of the Florida Administrative Code.
- Requirements that are specific to assisted living facilities are found in Chapter 429, Part I, Florida Statutes and Chapter 58A-4, Florida Administrative Code.

The Agency's approach to facility regulation centers on: identifying problems (through surveys, complaints or self-reporting); pinpointing their underlying cause(s); ensuring the facility has a plan to mitigate those causes and ensuring the facility effectively implements its plan.
The following tables provide basic statistics about regulatory actions the Agency has taken in ALFs. The first table shows the number of regulatory visits made by field staff in ALFs over the last five fiscal years. The visits include routine surveys, follow-up surveys and complaint investigations.

	FY 06/07	FY 07/08	FY 08/09	FY 09/10	FY 10/11
Number of Visits	6,274	6,892	6,060	6,455	6,327

Regulatory citations are documented in a Statement of Deficiencies sent to the licensee. Deficiencies are documented with a classification and scope to represent the severity of risk to residents on a scale of I to IV, Class I being most serious and Class IV being minor with no concern of resident risk. The most serious deficiencies are classified as "Class I" if they represent immediate danger to clients or a substantial probability of death or serious harm. Classification is defined in Health Care Licensing Procedures Acts section 408.813, F.S. and is uniform across all health care providers licensed by the Agency, except nursing homes which are aligned with the federal definitions. Classification of is defined in s. 408.813 (2), F.S. as:

(a)Class "I" violations are those conditions or occurrences related to the operation and maintenance of a provider or to the care of clients which the agency determines present an imminent danger to the clients of the provider or a substantial probability that death or serious physical or emotional harm would result therefrom. The condition or practice constituting a class I violation shall be abated or eliminated within 24 hours, unless a fixed period, as determined by the agency, is required for correction. The agency shall impose an administrative fine as provided by law for a cited class I violation. A fine shall be levied notwithstanding the correction of the violation.

(b)Class "II" violations are those conditions or occurrences related to the operation and maintenance of a provider or to the care of clients which the agency determines directly threaten the physical or emotional health, safety, or security of the clients, other than class I violations. The agency shall impose an administrative fine as provided by law for a cited class II violation. A fine shall be levied notwithstanding the correction of the violation.

(c)Class "III" violations are those conditions or occurrences related to the operation and maintenance of a provider or to the care of clients which the agency determines indirectly or potentially threaten the physical or emotional health, safety, or security of clients, other than class I or class II violations. The agency shall impose an administrative fine as provided in this section for a cited class III violation. A citation for a class III violation must specify the time within which the violation is required to be corrected. If a class III violation is corrected within the time specified, a fine may not be imposed.

(d)Class "IV" violations are those conditions or occurrences related to the operation and maintenance of a provider or to required reports, forms, or documents that do not have the potential of negatively affecting clients. These violations are of a type that the agency determines do not threaten the health, safety, or security of clients. The agency shall impose an administrative fine as provided in this section for a cited class IV violation. A citation for a class IV violation must specify the time within which the violation is required to be corrected. If a class IV violation is corrected within the time specified, a fine may not be imposed.

The following table shows the number of violations cited in ALFs over the last five fiscal years.

	FY 06/07	FY 07/08	FY 08/09	FY 09/10	FY 10/11	Total
ALF Surveys	1,726	1,897	1,725	2,114	2,105	9,567
Class I	60	41	55	25	109	290
Class II	256	242	260	215	351	1,324
Class III	11,151	12,025	10,262	12,506	11,696	57,640
Class IV	1,878	2,362	1,257	1,577	731	7,805
Total Class Violations	13,345	14,670	11,834	14,323	12,887	67,059

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Fiscal Year	ALF Fines Imposed by Final Order
06/07	$872,860.16
07/08	$815,073.27
08/09	$683,892.83
09/10	$636,555.50
10/11	$776,238.44

The following table shows the annual number of ALF license revocations and suspensions from 2006 to the present. The table also contains facilities that we have denied a licensure application and the number of facilities that closed or failed to renew while an action against the license was pending.

	FY 06/07	FY 07/08	FY 08/09	FY 09/10	FY 10/11	Total
Suspensions	3	6	2	1	2	8
Revocations	3	5	4	12	7	31
Denials of Active Licenses	8	6	11	7	5	37
Closed or Failed to Renew with legal cases (subject of all Closed/ Failed to renew)	38	34	37	40	46	195

Adverse Incident Reporting

Most state and national assisted living regulatory models include facility self-reporting of "adverse incidents" when a resident has experienced a significant accident or outcome. In Florida, ALFs are required by statute to report such adverse incidents to the Agency. Florida's assisted care adverse incidents are defined in statute (Section 429.23 F.S.) as:

(a) An event over which facility personnel could exercise control rather than as a result of the resident's condition and results in:

1. *Death;*
2. *Brain or spinal damage;*
3. *Permanent disfigurement;*
4. *Fracture or dislocation of bones or joints;*

5. Any condition that required medical attention to which the resident has not given his or her consent, including failure to honor advanced directives;

6. Any condition that requires the transfer of the resident from the facility to a unit providing more acute care due to the incident rather than the resident's condition before the incident; or

7. An event that is reported to law enforcement or its personnel for investigation; or

(b) Resident elopement, if the elopement places the resident at risk of harm or injury.

A facility is required to file a preliminary report with the Agency within one business day after the occurrence of an incident that appears to match one of the definitions above. The facility then has 15 days to complete its investigation of the incident and file its final report. This report must include a detailed description of the findings of the investigation. The facility is also required to report any cases of abuse, neglect or exploitation to the Department of Children and Families.

If an adverse incident report appears to describe any risk of a present and ongoing threat to residents, the report is referred to the Complaint Administration Unit in the Agency's Division of Health Quality Assurance. Additionally, all adverse incident reports are provided to the Consumer Services Unit in the Department of Health Medical Quality Assurance to determine if a regulated health care practitioner has engaged in behavior which may warrant inquiry and possible action by a licensing board or the Department of Health. Florida's adverse incident reporting program is limited, however, by debatable definitions of what constitutes an incident.

Civil Liability Claim Reports

When an assisted living facility is notified of a liability claim, section 429.23(5), F.S., requires the assisted living facility to, in turn, file a monthly report to the Agency. The report requires the name of the resident, dates of the incident and the type of injury or violation of rights alleged. The statute provides that the report is not discoverable in any civil or administrative action. The Agency publishes a report on its website demonstrating monthly, quarterly and annual aggregate data of the number of liability claims intended to be filed against assisted living facilities in aggregate – no individual facility names may be provided. The report informs the Agency and the public (providers and consumers) of the number of intended claims filed against all assisted living facilities.

Information reported is not used in any regulatory manner and may be incomplete as only actively licensed ALFs are required to report. If a licensee receives litigation notice after they close or sell the facility, they are no longer obligated to report. Given the very low number of reported claims for almost 3,000 licensed facilities, there is concern that this information may be under reported.

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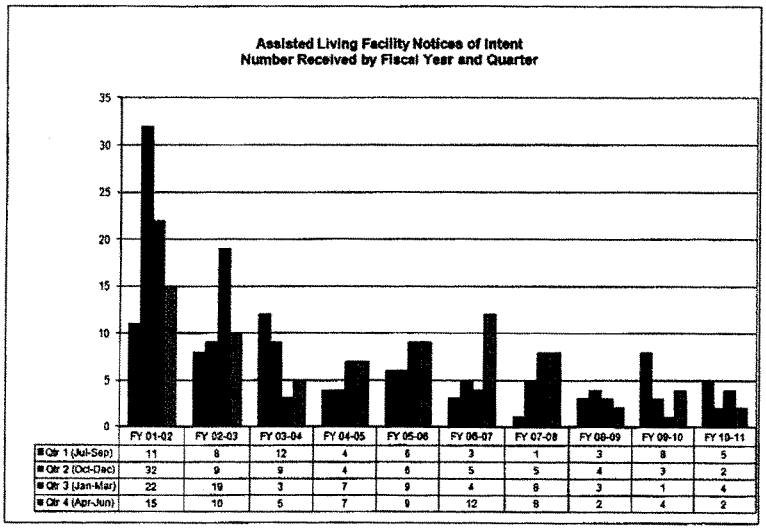
Two reports are produced. One shows the number of intended liability claim reports by fiscal year and quarter from FY 01-02 through FY 10-11 and the second one, the number of intended claims filed calendar year January 2010 – December 2010.

The Agency began collecting information from nursing homes regarding civil litigation in May, 2001. Initial reporting included notices of intent (NOI) to litigate for civil cases. Generally an NOI serves to notify the facility licensee of a plaintiff's intent to sue for some cause of action. Once initiated, cases may be withdrawn, settled or move forward to litigation as represented by a civil complaint.

The following charts provide information about the NOIs and civil complaints reported to the Agency. Data changes over time if reports are submitted late or in error. The most recent liability claim reports are provided at the link below: http://ahca.myflorida.com/MCHQ/Long_Term_Care/FDAU/docs/LiabilityClaims/ALF_Chart.pdf.



	FY 01-02	FY 02-03	FY 03-04	FY 04-05	FY 05-06	FY 06-07	FY 07-08	FY 08-09	FY 09-10	FY 10-11
Qtr 1 (Jul-Sep)	11	8	12	4	6	3	1	3	8	5
Qtr 2 (Oct-Dec)	32	9	9	4	6	5	5	4	3	2
Qtr 3 (Jan-Mar)	22	19	3	7	9	4	8	3	1	4
Qtr 4 (Apr-Jun)	15	10	5	7	9	12	8	2	4	2

Punitive damages awarded from assisted living facility litigation must be equally divided between the claimant and the state Quality of Long Term Care Facility Improvement Trust Fund and collected by the Department of Financial Services as specified in 429.298(4), F.S. The Fund authorized in 400.0239, F.S., was created in 2001 to support activities and programs directly related to improvement of care of nursing homes and assisted living facility residents, however no deposits have been made to this fund from assisted living facility cases.

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Roles of Government Agencies in Assisted Living

In addition to the regulatory oversight of licensure, several other government organizations are involved in assisted living facilities. The Agency works closely with each of these programs and communicates both at the local and headquarters offices. Primary agencies and their roles are described below followed by a chart of primary and other agencies involved in assisted living facilities.

Agency for Health Care Administration

- Health Quality Assurance: Licensing & Regulatory Oversight
- Medicaid: State Plan Reimbursement for Assistive Care Services (no reimbursement for residential ALF care), Medicaid Reimbursement through long term care waivers including Assisted Living and Nursing Home Diversion

Department of Elder Affairs

- Rule Development for Assisted Living and Adult Family Care Home
- Assisted Living Trainer Certification
- Comprehensive Assessment and Review of Long-Term Care Services (CARES) reviews Medicaid long term care placement
- Administration of the Nursing Home Diversion Medicaid Waiver
- Statewide Public Guardianship Office assists in guardianship services as appropriate
- State Long-Term Care Ombudsman Program State Long Term Care Ombudsman – Engages volunteer resident advocates to assist residents and families in dialogue with representatives of long term care facilities

Department of Children and Families

- Adult Protective Services – Investigates complaints of abuse, neglect or exploitation of vulnerable persons including those who live in long term care facilities
- Mental Health Clients in ALFs - assists in rule development for Limited Mental Health ALFs, facilitates case management for clients living in ALFs
- Specific Medicaid Waiver

Agency for Persons with Disabilities

- Developmentally Disabled Clients in ALFs
- Medicaid Developmental Disability Waiver clients in ALFs

Attorney General

- Medicaid Fraud Control Unit – The Attorney General's Office (AG) investigates allegations of Medicaid fraud. Administers the PANE Project, (Patient Abuse, Neglect and Exploitation), Operation Spot Check, and Attorney General staff may investigate abusive situations in long term care facilities.

Department of Health

- Health & Sanitation Inspections

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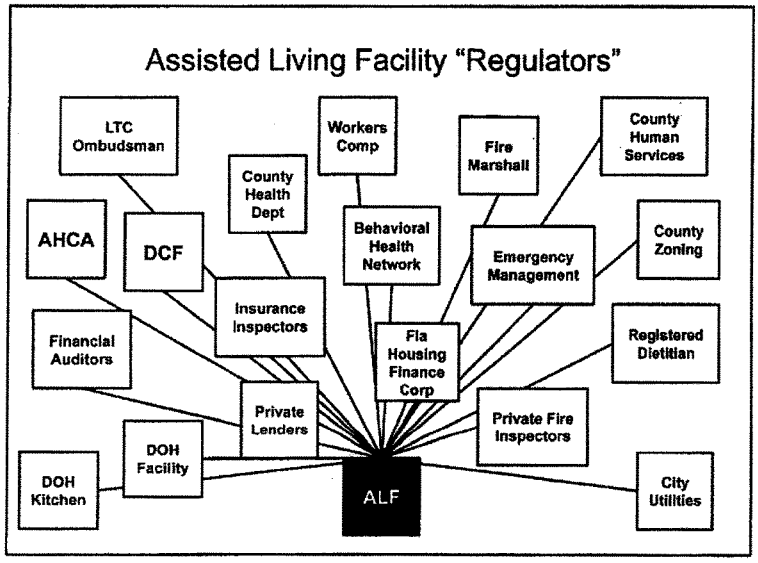
- Licensure & Regulatory Oversight of Health Care Practitioners working in Assisted Living Facilities

Local Authorities (ALF)

- Fire Authority – Fire and Life/Safety Approval
- Zoning / Building Code Approval and Enforcement

In addition to the other state agencies, there are a variety of state and local organizations that have some kind of regulatory authority over the operation of an ALF. The following illustration shows a number of the different types of organizations that may be viewed by assisted living licensees as having regulatory authority over some aspect of the operation of the facility.



Assisted Living Regulation in Other States

Nearly every state has experienced growth in similar types of "assisted living" facilities. Though use of the term "assisted living" is widespread, there is considerable state-to-state variation in the definition. The term is currently used by 41 states but refers to facilities licensed by states as personal care homes, residential care facilities, adult care homes, homes for the aged and other types of facilities. This variation in the definition of

assisted living complicates any effort to compare regulatory approaches and outcomes across states.

Few states approach the regulation of assisted living facilities in the same manner. The Agency for Health Care Research and Quality (AHRQ) has found that while all states license and regulate what they call assisted living facilities, these regulations "differ significantly both within and among states, in part because of the lack of a uniform definition of assisted living." In 1999, the U.S. Government Accountability Office (GAO) found that in general, "State reviews occur every 1 to 2 years, and the results of monitoring activities varied." An AHRQ review of the Web sites of state licensing agencies found that 48 states post licensing regulations; 46 provide access to a database or list of licensed facilities; 12 post survey findings on their Web site; and 14 states post a guide to help consumers learn about and choose a facility. Twenty six states offer information to facility administrators and staff on a Web site. The information ranges from licensing application and renewal forms, administrator requirements, bulletins, information about the survey process, technical assistance materials, and incident and complaint forms.

A quick look at assisted living facility regulation in other states illustrates the variation in approach:

California

California's Department of Social Services licenses what are known as "residential care facilities for the elderly" (RCFEs). The licensing agency no longer annually inspects RCFEs and now randomly selects and inspects 20 percent of the licensed facilities each year. The selection is structured to ensure that every facility is inspected at least every 5 years. Surveyors use a manual that guides the inspection process. The inspection includes interviews with residents and staff and record reviews. The surveyor determines the number of interviews he or she conducts at each facility. Standard protocols are not used. The State expects to make inspection reports available to the public on its Web site in the near future.

Legislation enacted in 2003 requires unannounced inspections of facilities that are on probation, have pending complaints, operate under a plan for compliance, or must have an annual inspection because the facilities receive payment from Medicaid. Inspectors also verify that residents who were required to move from the facility by the department are no longer at the facility.

Texas

The Texas Department of Aging and Disability Services (DADS) licenses assisted living facilities. Facilities are licensed and inspected annually. The inspection team consists of a registered nurse, social workers, and a life safety code specialist. During the inspection, surveyors meet with the person in charge, review the process, and request lists of residents and staff, schedules, training records, incident reports, policies and procedures, the services provided, and the facility's disclosure form. During a tour, the surveyor observes the general operation of the facility and resident activities. General interviews are held with a sample of residents, family members, and staff. A sample of

resident records is also reviewed. Residents are asked if they are satisfied with the facility, the services, and food. If they are not satisfied, they are asked for details that may be explored with the manager. Survey reports may be posted at the facility or requested from the department.

New York

New York's Department of Health issues licenses for "adult care facilities" for four years. Facilities are inspected at least annually but no longer than every eighteen (18) months. Inspections include, but are not necessarily limited to, examination of the medical, dietary, and social services records of the facility, as well as the minimum standards of construction, life safety standards, quality and adequacy of care, rights of residents, payments, and all other areas of operation. Two inspections per year are conducted for private proprietary adult homes.

Other types of inspections include:

- Complete inspections prior to certification or renewal
- Complete inspections when there are serious or continual deficiencies
- Summary inspections to determine compliance with key regulatory provisions in all areas of operation
- Partial inspections to examine specific areas of operation
- Inspections in response to a complaint to determine the validity of the complaint
- Follow-up inspections to determine whether deficiencies have been corrected
- Other inspections as necessary

In 2002, New York implemented new policies regarding the oversight of adult homes that included: reinforcement of mandatory death reporting by homes and immediate investigations of such reports; multi-agency profiles of deaths at the homes to identify patterns; and increased surveillance.

Alabama

The State of Alabama does not have a mandated time frame in which to visit every facility and is working on implementing a three year cycle. Alabama implemented a system for rating residential facilities in 2004. Using survey findings, facilities are rated green if they have minor deficiencies, yellow if they have a problem that could pose a substantial risk to residents, or red if the survey found serious risk to residents. Facilities rated red receive full surveys. Shorter surveys are conducted for facilities rated green or yellow. The Alabama scoring system arranges deficiencies into three categories: routine deficiencies that have limited potential for harm; systemic or substantial risk deficiencies that have a high potential for harm; and critical deficiencies that result in actual harm and lead to mandatory enforcement. Routine deficiencies present minimal risk to residents and receive a score only if more serious deficiencies are not present.

Georgia

The Georgia Office of Regulatory Services (ORS) conducts initial, annual, follow-up inspections and complaint investigations of residential facilities. Inspections are generally conducted on an unannounced basis. ORS has the authority to take the following actions against a licensee: fining; license restriction, suspension or revocation;

"blacklisting" of individuals or public reprimand. Fines and revocations are the most common actions. Surveyors interview six residents and staff members or ten percent of the residents, whichever is greater, using open-ended questions that elicit information about their well-being, length of stay, how they are treated, if they have had any problems and how they were resolved, and whether they know of problems that other residents have had.

Ensuring Quality and Oversight in Assisted Living

November 2, 2011

Statement of the National Association of State Long-Term Care Ombudsman Programs

to the Senate Special Committee on Aging

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The National Association of State Long-Term Care Ombudsman Programs appreciates the Special Committee on Aging's attention to the quality of assisted living.

Although "assisted living" is different in every state, the expansion of assisted living as an alternative to (sometimes) more costly nursing home care is a national trend that deserves federal oversight. The federal government involved itself in assisted living when the Centers for Medicare and Medicaid Services began approving Medicaid waivers to states and it is time to take the next steps to ensure quality of care and protection from harm. Such waivers allow states to draw federal match to pay for nursing home level of services in residential environments. CMS requires quality assurance of waiver services and states may require basic standards for licensing or otherwise regulating the facilities. Bifurcating oversight in this way makes it difficult for consumers seeking resolution of problems they may encounter. Additionally, access to a long-term care ombudsman as an independent advocate is sporadic throughout the country due to insufficient resources in the ombudsman program and inconsistent requirements that homes inform residents about the ombudsman program.

NASOP advocates development of comprehensive standards and oversight of assisted living. Nursing homes are increasingly changing their business model to focus on short-term rehabilitative care, in part to attract higher reimbursement through Medicare than they receive through Medicaid. One result is that we are seeing yesterday's nursing home residents becoming today's assisted living residents. Many assisted living facilities hold themselves out as providing dementia care, advertising secure environments and specialized units. Through Medicaid waivers, elders and adults with disabilities, who by definition require nursing home level of services, are receiving care in residential environments. However, regulation of residential environments has not evolved with the population changes, creating the potential for crises such as those Senator Nelson described in his introductory remarks.

We recognize that some flexibility may be in order because not all assisted living providers offer the level of service described here. However, basic resident rights should be consistent among states. We recommend enactment of a federal bill of rights for residents of assisted living and a regulatory approach that demands a culture of safety and promotes high quality of care and quality of life. Additionally, the Long-Term Care Ombudsman Program should be adequately funded to respond consistently to

complaints about assisted living and to provide a regular presence in every state. Residents of assisted living facilities are often just as vulnerable as residents of nursing homes were in the 1960s and it is time for public policy to catch up.

Thank you for this opportunity to provide our statement. We appreciate the Committee's interest in this matter.

ncal®
National Center for Assisted Living

STATEMENT
Of
The National Center for Assisted Living

For the

U.S. Senate Special Committee on Aging Hearing:

"Ensuring Quality and Oversight in Assisted Living"

November 2, 2011

The National Center for Assisted Living (NCAL) represents more than 2,900 assisted living providers nationwide, and is the assisted living voice of the American Health Care Association (AHCA). NCAL commends the U.S. Special Committee on Aging, Chairman Herb Kohl of Wisconsin and Ranking Member Bob Corker of Tennessee for convening this hearing, chaired by Sen. Bill Nelson of Florida.

There is no more important issue facing this Committee than ensuring quality and oversight of assisted living communities and the more than one million residents they serve nationwide. The failure of Florida's regulatory system to ensure quality care in several of the state's assisted living facilities, as documented in a *Miami Herald* series and during today's hearing, is unacceptable and must be addressed. Florida's Agency for Health Care Administration and the state legislature, along with key stakeholders, have begun implementing changes to ensure that the state's seniors and people with disabilities receive quality care with vigorous oversight.

NCAL supports this effort and its Florida affiliate is participating on the Governor's Assisted Living Facility Workgroup, which will be making regulatory recommendations to the state legislature.

As policymakers put these changes in place, we would like to highlight several issues. While what occurred in Florida is unacceptable, similar regulatory failures are not happening in the vast majority of other states. NCAL believes that states are the appropriate government bodies to regulate assisted living and that state regulation and enforcement should be strong and adequately funded. States now have a long track record of innovative and responsive regulation of assisted living settings.

Many of the issues that have arisen in Florida concern care for a population with mental health needs that is different from the typical senior assisted living population. Policymakers need to ensure that people with mental health needs are placed in facilities that can meet their needs and that adequate resources are provided for their care.

Many cases of substandard care involve residents receiving coverage under Florida's Medicaid program. Government funding for care must be adequate to meet the needs of all beneficiaries regardless of the site of service. We understand that this is a difficult issue to raise in these times of budget austerity, but adequate funding for Medicaid and other programs serving low-income elderly and people with disabilities simply must become a priority, both at the state and national levels. In assisted living settings, Medicaid only covers the cost of services, not room and board. And Medicaid typically pays far below the cost of providing care – often at rates two to three times lower than what private-pay residents pay.

Assisted Living: A National Perspective

Today, in the United States, more than one million Americans make their home in assisted living/residential care communities, including about 131,000 receiving assistance under the Medicaid program. Seniors and their families opt for assisted living because of its emphasis on empowering residents' freedom to live their lives as they wish, with dignity, while providing them with needed services and supports. Assisted living continues to grow and focus on consumers' wants, needs, and preferences.

The majority of assisted living residents and their families view their assisted living communities very favorably, according to a recently released survey by "My InnerView," a national organization with expertise in data collection and measuring long term care consumer satisfaction. Residents had an overall satisfaction rating of 91 percent (excellent or good) and family members had an overall satisfaction rating of 93 percent (excellent or good) with their respective assisted living community. A key benchmark in satisfaction surveys is the category of

"recommendation to others." My InnerView's data reveals that 91 percent of the residents who responded were willing to recommend their assisted living community to others and 94 percent of the family members who responded felt the same. This report was compiled as a result of surveying residents, family members, and employees of nearly 1,400 assisted living communities from across 48 states. My InnerView collected information from 35,680 customers and 13,074 staff members.

From an employee perspective, 76 percent of staff were satisfied (excellent or good) with the assisted living community. Furthermore, 86 percent of the staff were willing to recommend their assisted living community as a place to receive care (excellent or good) and 76 percent of the staff were willing to recommend their community as a place to work (excellent or good.) (Employee satisfaction is measured because it correlates with the quality of care.) My InnerView's report delves deeper into specific areas of satisfaction and areas where improvement is suggested. For a copy of the report, go to www.myinnerview.com.

NCAL's Perspective

As the Committee hears testimony today, NCAL would like to offer the following perspectives:

- Assisted living is a dynamic, resident-centered and cost-effective long term care model that is a vital option for seniors and people with disabilities.
- Regulation of assisted living should remain at the state level. The body of state laws and regulations relating to assisted living has evolved steadily since the Assisted Living Workgroup issued its report in 2003. States have responded as assisted living has expanded and accommodated residents with higher levels of needs.
- The assisted living profession has taken many steps toward innovative quality improvements and developing measurements of quality. These efforts need to be nurtured by public policymakers.
- The issues facing Medicaid coverage in assisted living are fundamentally economic. Sub-market Medicaid payment rates, lack of payment for room and board, and restrictive state policies are the root causes of limited options for low-income seniors in many states.
- Even though public funds remain limited, it is imperative for policymakers to consider ways to expand the availability of affordable assisted living and to help states cover the gaps in Medicaid funding for assisted living. Broadly speaking from a national perspective, policies that could be considered include: making housing vouchers available to low-income assisted living residents including Medicaid beneficiaries; providing increased public financing or loan supports for construction of affordable assisted living; building a housing financing component into or alongside Medicaid services payments for beneficiaries living in community-based settings, including assisted living; and expanding incentives and financial vehicles for individuals and families to save for future long term care costs.

- The Centers for Medicare & Medicaid Services' (CMS') proposed rules seeking to define Medicaid community-based settings should include all types of assisted living communities participating in Medicaid. As currently worded, these proposed rules would eliminate funding for most of the residents receiving Medicaid services in assisted living communities, forcing them into more costly institutional settings. Under the logic of the landmark Olmstead Supreme Court decision, depriving Medicaid beneficiaries of a major type of housing with services—assisted living—would be the opposite of a reasonable accommodation, especially for those seniors who prefer to live in assisted living and those for whom assisted living is the least institutional option available based on their clinical needs.

Assisted Living Residents and Philosophy of Care

Assisted living is a growing and dynamic form of residential care, serving primarily elderly people and individuals with disabilities. Assisted living is more than a physical setting—it embraces a philosophy of care. Created in response to customer preferences and demand for individual-centered care, assisted living residences provide assistance with physical activities and health-related needs. They also strive to meet the social, emotional, cultural, intellectual, and spiritual well-being of residents.

Assisted living has evolved in a variety of models based on consumer preferences and regional differences. As a result, states take a variety of approaches in overseeing the industry and establishing standards. While assisted living is the most common term used in the nation both by the industry and state regulatory agencies, assisted living settings may be known by different names, including, but not limited to, residential care, personal care, adult congregate care, boarding homes, and domiciliary care. Regardless of what they are called, assisted living communities typically are:

- Congregate residential settings that provide or coordinate personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities and health-related services, and that include at least one awake staff member at all times;
- Designed to minimize the need to move;
- Designed to accommodate individual residents' changing needs and preferences;
- Designed to maximize residents' dignity, autonomy, privacy, socialization, independence, choice, and safety;
- Designed to encourage family and community involvement; and
- Settings that provide assistance in maintaining and enhancing the physical, emotional, intellectual, social, and spiritual well-being of residents based on their preferences.

Assisted living also encourages:

- The personal development of residents, on an individual basis;
- Physical activity that maintains and enhances fitness;

- Family and community involvement; and
- Development of positive relationships among residents, staff, families, and the community.

(See "NCAL's Guiding Principles for Assisted Living," available at http://www.ahcancal.org/ncal/about/Documents/GPAssistedLiving.pdf.)

Resident Profile

The typical assisted living resident is a middle-class, widowed 87-year-old woman on a fixed income. Residents' median income is less than $19,000 a year, according to the "2009 Overview of Assisted Living," a national study sponsored by five industry groups. About 66 percent of assisted living residents have hypertension; 42 percent have arthritis; 38 percent have Alzheimer's disease or other dementias; 33 percent have coronary heart disease, and 30 percent suffer from depression, according to the study. Residents on average take about 10 medications and more than 80 percent needs help managing their medications. On average, 64 percent of residents need help with bathing, 39 percent with dressing, and 26 percent with toileting.

Regulation of Assisted Living/Residential Care

Although many federal laws impact assisted living, regulation of assisted living occurs primarily at the state level. Though state licensure terms vary[i], there is much commonality in the range of services that assisted living communities provide across the country. Assisted living communities provide housing with services, including assistance with activities of daily living, such as dressing and bathing, and help with medication administration. Many assisted living communities provide specialized services for people with Alzheimer's disease or other dementias.

The body of state laws and regulations has grown steadily.[ii] All 50 states and the District of Columbia regulate assisted living/residential care facilities. The continuing development of the body of state law and regulations governing assisted living is described in several reports including the Department of Health and Human Services' (HHS') "Assisted Living and Residential Care Policy Compendium, 2007 Update," (which is updated every few years) and NCAL's annual "Assisted Living State Regulatory Review." Research conducted for the 2011 edition of NCAL's "Regulatory Review" shows that more than a third of states changed their assisted living/residential care laws or regulations over the past year, a rate of change similar to what has been happening since 2003. States have responded as assisted living has grown and as some communities serve residents with more complex health and chronic care needs. While state assisted living regulation remains a work in progress and is not always perfect, states generally have responded to issues that have arisen and adjusted their regulatory systems appropriately and in a timely manner.

In 2010 and January 2011, even though the pace of regulatory change slowed somewhat as states faced enormous fiscal pressures, at least 18 states reported making statutory, regulatory, or policy changes impacting assisted living/residential care communities, according to data collected for the 2011 edition of NCAL's "Assisted Living State Regulatory Review." At least six states made major changes including Idaho, Kentucky, Oregon, Pennsylvania, South Carolina, and Texas. Focal points of state assisted living policy development in 2010 include life safety, disclosure of information, Alzheimer's/dementia standards, medication management, background checks, and regulatory enforcement. Other areas of change include move-in/move-out requirements, resident assessment, protection from exploitation, staff training, and TB testing standards.[iii]

As assisted living has evolved, states have acted to protect vulnerable populations. According to HHS' "Assisted Living and Residential Care Policy Compendium," in 2007, 45 states had requirements for residential care facilities serving residents with Alzheimer's disease and other dementias (up from 44 states in 2004, 36 in 2002, and 28 in 2000).[iv] And the number of states with rules specifically geared for the care of assisted living residents with Alzheimer's disease has grown since then. In 2009, for example, Georgia, New Mexico, and Iowa created or added to protections for residents with Alzheimer's disease or other dementias.[v]

Almost all states require specified information in residency agreements. The HHS report noted the following state disclosure requirements within residency agreements:

- Services included in basic rates – required by 49 states.
- Cost of service package – 44 states.
- Rate changes – 30 states.
- Refund policy – 30 states.
- Cost of additional services – 28 states.
- Admission/discharge information – 28 states.

States continue adding to disclosure requirements and are placing more information on their web sites concerning assisted living facilities.

According to the HHS report, while only a few states do not allow individuals who meet the state's minimum nursing level of care criteria to receive care in assisted living settings, no states allow persons needing a skilled level of care to be served in an assisted living setting for an extended period of time (needing 24-hour-a-day skilled nursing oversight or daily skilled nursing services).[vi] States take different approaches for setting admission/retention policies and can be group into three categories (or combinations thereof):

- Full continuum (e.g., OR, HI, WA, ME). These states allow assisted living facilities to serve a wide range of needs.

- Discharge triggers. These states specify a list of medical needs or treatments that cannot be provided in assisted living communities and that will result in discharge (e.g., TN, VA).
- Levels of licensure (e.g., AZ, AR, FL, UT). Assisted living facilities are licensed based on needs of residents. In recent years, more states have moved to different levels of licensure.

NCAL's "Assisted Living State Regulatory Review" tracks and summarizes state regulations in several categories including the licensure term, definition, disclosure rules, facility scope of care, third party scope of care, move-in/move-out requirements, resident assessment, medication management, physical plant requirements, residents allowed per room, bathroom requirements, life safety, Alzheimer's unit requirements, staff training for Alzheimer's care, staffing requirements, administrator education/training requirements, staff education/training requirements, continuing education requirements, and Medicaid coverage. These rules have evolved steadily as have the many other aspects of assisted living that states regulate that are not included within the scope of the report.

Regulation of Assisted Living Should Remain at the State Level

NCAL strongly supports regulation of assisted living at the state level. NCAL believes that all assisted living/residential care communities should be licensed or certified by the states and surveyed by the states at reasonable regular intervals. States should provide adequate funding to perform periodic surveys at least every two years and conduct timely surveys in response to complaints or issues of a serious nature as they arise. NCAL also believes that providers that have historically demonstrated a high level of customer satisfaction and excellence should be rewarded. For example, providers demonstrating excellence could be recognized for excellent performance on a public web site or surveyed less frequently.

While some argue that the federal government should extend its system of regulation for nursing facilities to encompass assisted living/residential care communities, NCAL opposes this for many reasons. For one thing, federal government regulation of nursing homes has not been an unblemished success story. It is punitive in nature and gives providers little, if any, incentive for quality improvement. Federal regulation of nursing homes, along with sub-market Medicaid reimbursement levels, has played a key role in creating and rigidifying a medical model of housing with services and making it difficult for the nursing home industry to update physical plant and improve quality. Despite these challenges, the nursing home industry has documented quality improvements in recent years. In addition, federal regulation has been slow to keep pace with the evolution of nursing homes. Just last year, CMS put into place new rules recognizing the culture change movement – years after the movement began transforming nursing home settings and creating more home-like environments. On the other hand, state governments have a long history of responding quickly on the regulatory front to changes occurring in assisted living.

In order to meet the needs of different types of consumers, assisted living communities come in many models and designs. Assisted living can be provided in a high-rise building housing several hundred individuals, in a small home with just a few residents, or within a campus offering many levels of care. The key to assisted living is providing resident-centered care in a secure setting that respects individual lifestyle choices, dignity, and privacy. Living accommodations can include a full size apartment, a single room, or living with another person. In some facilities, services are limited to meal preparation, housekeeping, medication reminders, and minimal assistance. In others, more intensive services, including help with administering medications, on-site nurses, and regular assistance with daily activities such as bathing and dressing are available. Assisted living also can be a very good place for many people with Alzheimer's to live, with specially designed communities and program to meet their needs. There is no need to impose uniformity in senior housing, including assisted living. People seeking assisted living services should have a wide array of choices, unlike the current situation with highly regulated nursing homes. States are best positioned to regulate assisted living, especially since there is wide variation among states on the types of housing available, availability and support for community-based settings, and definitions of what is considered an institutional level of care under the Medicaid program.

An important difference between assisted living and nursing homes is the primary source of financing. Federal regulation of nursing homes arose in part because the federal government paid for much of the physical plant (through the Hill-Burton Act) and continues to pay for most nursing home care through the Medicare and Medicaid programs. While federal/state Medicaid programs finance care for more than 60 percent of nursing home residents, Medicaid finances care (services only – not board and care costs) of only about 13 percent of assisted living residents. Assisted living is primarily financed with private-sector dollars. Because of this, market forces can exert more influence on the level of quality in assisted living facilities than nursing homes: private-pay residents unhappy with the care they receive are more likely to be able to move to another facility than those relying on government programs with limited choices.

States continue developing oversight of assisted living/residential care, even though some are now facing major budget constraints. According to a 2006 report by the U.S. Agency for Healthcare Research and Quality (AHRQ), all states reported that they receive and investigate complaints in assisted living settings.[vii] Oversight and monitoring of assisted living facilities vary by state; much like nursing home inspections, assisted living surveyors follows protocols to enforce licensing requirements and standards. According to the report, the typical survey process includes an annual unannounced inspection of the facility. While a few states do not provide enough funding to perform surveys required under their statutes, most are doing at least an adequate job of inspecting assisted living facilities. The five state regulators participating in the Aging Committee's assisted living roundtable discussion on March 15 all testified that their states were doing a good job of regulating the industry.

The AHRQ report also mentions a few states that have begun using collaborative approaches toward assisted living oversight.[viii] Rather than moving assisted living to the federal regulatory approach that has been taken for nursing homes, policymakers should follow the lead of states such as Wisconsin that have taken a more collaborative approach with assisted living regulation and oversight.[ix]

A 2010 report, published by the Long Term Care Community Coalition (LTCCC) and titled "Overview of State Survey and Enforcement Laws, Regulations and Policies for Assisted Living," found that state departments of health or departments of social services conduct oversight of assisted living facilities. In some states, multiple state agencies are involved. The report found that most states inspect assisted living facilities annually, biannually, biennially or over a specified time spanning one to two years. While a building's initial survey may be announced, most subsequent surveys are unannounced. According to the LTCCC report, surveyors typically examine if residents are informed of their rights, resident assessments, care plans, resident satisfaction surveys, staff criminal background checks, and availability of past inspection reports. Almost every state requires that copies of inspections either be posted or made available upon request. At least two states now post deficiencies on their web sites.

Survey teams should interview residents, family members, and caregivers, and observe staff, and not simply do paper reviews of records. NCAL believes that successful survey protocols should examine resident and family satisfaction findings and examine staff satisfaction due to its correlation with quality care. NCAL also believes that it makes sense to allow abbreviated surveys for communities with a consistent track record of good surveys. This would allow states to focus their limited resources on communities lacking consistent good performance. We believe the separate complaint survey systems that states have in place would identify issues that might arise between abbreviated surveys.

Quality Initiatives & the Importance of Person-Centered Care

The assisted living industry has been identifying best practices and key resources for assisted living providers nationwide. At its last meeting, in April of 2003, the Assisted Living Workgroup provided the Senate Special Committee on Aging a comprehensive compendium of more than 100 recommendations designed for consistent quality in assisted living communities. These recommendations spanned seven different areas and were agreed upon through a consensus process.

Since 2003, the assisted living profession has continued collaborative efforts of identifying and developing best practices through a variety of organizations. NCAL has been part of many of those efforts. NCAL participated on a national task force organized by the National Multiple Sclerosis Society (NMSS) in 2004. From this effort, the NMSS published a 46-page document for assisted living providers to better serve those residents with Multiple Sclerosis (MS) residing

in assisted living. The guidelines outline what MS is, its set of clinical conditions, and how to maximize the quality of life for those living with MS. These guidelines may be found on the NMSS Web site at http://www.nationalmssociety.org/search-results/index.aspx?q=assisted+living&start=0&num=20.

In 2006, NCAL was part of a collaborative effort sponsored by the Alzheimer's Association that developed Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes. These guidelines offer providers of long term care strategies for improving the quality of care provided to and quality of life experienced by the residents of assisted living. The guidelines cover six areas of care including food and fluid consumption, pain management, social engagement, wandering, falls, and physical restraints. NCAL provided copies of these guidelines to its entire membership for review and adoption. The guidelines may be found at http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf.

In 2009, NCAL was invited to review the work of the American Medical Directors Association on Caregiver Communication, Medication Management, and Diabetes Management. All three tools were developed for assisted living providers as resources to provide quality care for their residents. These resources may be accessed at http://www.amda.com/resources/alproducts.cfm#ALDIAB.

As a result of the Assisted Living Workgroup, the Center for Excellence in Assisted Living (CEAL) was formed in 2004 and is a national non-profit collaborative organization of 11 organizations. One of CEAL's major objectives is to foster high quality care through creating resources and acting as an objective source of information to facilitate quality improvement in assisted living; increasing the availability of research on quality practices in assisted living; establishing and maintaining a national clearinghouse of information on assisted living; and providing resources and technical expertise to facilitate the development and operations of high-quality, affordable assisted living programs to serve low- and moderate-income individuals.

Additionally, CEAL has published two white papers on topics including person-centered caring and medication management. CEAL is near completion in its newest resource in collaboration with Med-Pass, an Infection Control Pocket Guide designed for use by all staff in assisted living communities. In 2010, CEAL began its relationship with Med-Pass to create a Medication Administration Pocket Guide for Medication Technicians. More information may be found at www.theceal.org. In 2009, CEAL became a collaborative partner with the AHRQ to assist in the development of a consumer disclosure tool to assist consumers in their search for the best community for their loved ones.

NCAL's state affiliate in New Jersey, the Health Care Association of New Jersey, has a best-practices web site which lists best practices for Medication Management, Fall Management, Pain

Management and Performance Improvement. These resources may be found at http://www.hcanj.org/bestpractices.htm.
NCAL developed its Advocating Care Excellence (ACE) initiative in 2009 to demonstrate its commitment to quality and performance excellence in assisted living. NCAL believes that successful quality initiatives raise the bar for resident satisfaction, quality of life, and improved operational performance. NCAL's ACE houses all of NCAL's current quality resources and tools. All of NCAL's work towards quality care is based on NCAL's series of Guiding Principles:

- Guiding Principles for Assisted Living
- Guiding Principles for Consumer Information
- Guiding Principles for Dementia Care in Assisted Living
- Guiding Principles for Leadership in Assisted Living
- Guiding Principles for Quality in Assisted Living

These five documents serve as the foundation for all of NCAL's Inservice Training Tools and Quality Resources that it develops for its membership.

In 2010, NCAL launched its Performance Measures Initiative aimed at identifying and collecting data on areas that lend themselves to high quality care and quality of life for the residents and staff living and working in assisted living communities. NCAL collected data on its Tier I Performance Measures, those elements that contribute to increased quality of life for residents residing in assisted living.

In 2011, NCAL surveyed its members for a second year on the Tier I Performance Measures. NCAL's response rate increased significantly and gave us data to begin comparisons and identify trends and opportunities. Copies of the 2011 NCAL Performance Measure Report can be obtained by contacting NCAL's director of workforce and quality improvement or may be downloaded from the NCAL website, www.ncal.org. This latest survey report was based on a 25 percent response rate of the NCAL membership. Of those responding, some of the key findings include:

- 89 percent of the communities measured resident and family satisfaction;
- 94 percent of the communities reviewed incident reports for residents;
- 94 percent of the communities reviewed incident reports for staff;
- 97 percent of the communicates had a licensed nurse available to the staff and residents 24 hours a day (through various means); and
- 99 percent of the communities conducted criminal background checks on all new employees.

NCAL is currently in the final development of its Tier II Performance Measures, or those elements that contribute to an increased level of quality care. These initial measures will likely

include collecting data on falls, pain management, weight change, pressure ulcers, infection control, medication management, hospitalizations, elopements, depression, and advanced care planning. We are working to incorporate these measures into future surveys of the NCAL membership in 2013.

Medicaid Coverage and Assisted Living

Over the years, the primary issues facing Medicaid coverage for assisted living have been economic, not regulatory. And this is even more the case today as many states facing huge budget shortfalls now contemplate deep and painful cuts in programs serving low-income Americans.

Medicaid coverage in assisted living is much more limited than Medicaid coverage for nursing homes. While nursing home coverage is a mandated benefit under Medicaid, states have the option to cover assisted living services under the program. Furthermore, under Medicaid waivers, states can limit assisted living Medicaid coverage to a geographic area or to a certain number of slots. This is not the case for nursing homes. Under the Medicaid program, assisted living is considered a home and community-based (HBC) setting and consequently Medicaid does not pay the cost of room and board, utilities, and food. These gaps in Medicaid financing mean that states must consider a number of design decisions to finance costs that Medicaid does not cover. As a result, financing streams for assisted living receiving Medicaid tend to be very complex and funding for residents receiving Medicaid tends to be vastly lower than private-pay funding.

The latest study detailing national and state-by-state Medicaid payment and policy for assisted living was prepared by independent researcher Robert Mollica in 2009.[x] Entitled "State Medicaid Reimbursement Policies and Practices in Assisted Living," the report updated previous research done by HHS and detailed the wide variation in how states determine Medicaid payment levels for assisted living communities and other related policy issues. Among the findings is that the number of people receiving Medicaid coverage in assisted living communities grew significantly from 2007 to 2009 after virtually no growth over the previous three years. The report describes how states respond to the lack of Medicaid funding for room and board costs in determining a variety of policies, including whether or how much states supplement payments for room and board; whether states allow families and individuals to supplement room and board payments for Medicaid beneficiaries; and whether states allow beneficiaries to share apartments, and under what conditions.

Among the major findings were the following:

- The number of people receiving Medicaid coverage for services in licensed assisted living settings increased 9.2 percent between 2007 and 2009, and 43.7 percent between 2002 and 2009.

- Nationwide, about 131,000 low-income frail elderly Americans received services in assisted living communities under the Medicaid program (about 134,500 if programs with state-only funding are included).

- Thirty-seven states provided coverage under §1915 (c) home and community based services waivers to cover services in residential settings; thirteen states provided coverage directly under their state Medicaid state plan; four included services in residential settings under §1115 demonstration program authority; and six used state general revenues. States may use more than one funding source.

- Tiered rates were the most common methodology for reimbursing assisted living providers (19 states) and flat rates were used in 17 states.

- Twenty-three states capped the amount that may be charged for room and board.

- Twenty-four states supplemented the beneficiary's federal Supplemental Security Income (SSI) payment, which states typically use as the basis for room and board payment. SSI payments combined with state supplements ranged from $722 to $1,350 a month depending on the state. Some states provide no supplement.

- Twenty-five states permitted family members or third parties to supplement room and board charges.

- Twenty-three states required apartment style units; 40 states allowed units to be shared; and 24 states allowed sharing by choice of the residents.

- Screening for mental health needs was performed by case managers and assisted living community staff in nine states; by case managers only in 10 states; and by assisted living staff only in nine states.

- Mental health services were arranged by assisted living communities in 16 states; case managers in 20 states; and may be provided directly by assisted living communities in three states.

While Medicaid does not pay for room and board in assisted living settings, payment rates for Medicaid services are typically lower than private market rates. Gaps in the funding system

drive many of the other problems facing Medicaid coverage in assisted living. Room and board typically comprises about 40-50 percent of the cost of assisted living and the SSI payment of $674 a month is often inadequate, even in instances where states supplement SSI to help cover the costs of housing, food, and utilities.

Given the core economic issues described above, NCAL strongly opposes proposals to force providers to accept Medicaid coverage or to accept Medicaid-specified amounts as the entire payment. NCAL believes that families should be able to supplement room and board payments for residents receiving Medicaid coverage so that they can afford single-occupancy units.

Providing quality Medicaid coverage will become even more difficult in 2014 when assisted living providers, like other employers, will have to comply with the new coverage expansion mandates in the Affordable Care Act. Because industries with high percentages of low-wage workers, including long term care, tend to have relatively high percentages of uninsured and underinsured workers, complying with the law's health insurance coverage expansion requirements will cause their labor costs to increase significantly. While AHCA/NCAL supports efforts to expand health coverage, Medicaid rates will need to be adjusted to account for these added costs.

Despite these concerns, and even though public money is currently scarce, it is imperative for policymakers to consider ways to help states cover the gaps in Medicaid funding. Policies that could be considered include making housing vouchers available to low-income assisted living residents including Medicaid beneficiaries, providing increased public financing for construction of affordable assisted living, and expanding incentives and mechanisms for families to save for future long term care costs.

CMS Attempt To Define HCB Settings, Combine Waivers Raises Concerns

CMS' ongoing attempt to define Medicaid home and community-based settings for the first time has the potential to exclude many assisted living providers from the Medicaid program, thereby dramatically reducing access to needed housing and services to low-income individuals. As currently worded, CMS's proposed rules ("Medicaid Program: Community First Choice Option," *Federal Register*, Feb. 25, 2011 and "Medicaid Program; Home and Community-Based Services Waivers" *Federal Register*, April 15, 2011) will reduce long term care options for Medicaid beneficiaries. If these rules are not changed, they would force the majority of the more than 131,000 Medicaid beneficiaries currently living in assisted living communities to be transferred to a nursing home setting.

Both proposed rules would disqualify a community-based provider, such as assisted living or a group home, from participation in Medicaid by virtue of being on or near a property containing an institutional setting. Many seniors choose to live in settings offering multiple levels of care (e.g., continuing care retirement communities), and states have chosen to allow Medicaid to pay

for these. At a time when we have more seniors than ever before, CMS should not restrict the options available to seniors and the states.

The several other conditions that assisted living communities must meet in order to qualify as a Medicaid community-based setting under the April 15 proposed rule would decrease access and choice for Medicaid beneficiaries. Of great concern is the requirement that the residents have a lease. In most states, assisted living communities use resident agreements because they offer a unique combination of services and housing. This and the other requirements, such as having lockable doors and forbidding settings targeted to a particular diagnosis, could disqualify assisted living communities in several states from delivering care for the most vulnerable seniors, particularly those with Alzheimer's disease.

While we agree with the intent to integrate Medicaid beneficiaries into the larger community and have person-centered care, the proposed definitions would have the opposite effect. Many of these older Medicaid beneficiaries do not have the option of returning to their home, or their needs can no longer be met through home health care alone. Denying access to assisted living and group home settings would force older low-income residents into nursing homes and other institutional settings because, in most cases, there is no other housing with services for them.

CMS' proposed rule implementing the Community First Choice Option states "that certain settings are clearly outside of what would be considered home and community-based because they are not integrated into the community . . . home and community settings would not include a building that is also a publicly or privately operated facility which provide inpatient institutional treatment or custodial care; or in a building on the grounds of, or immediately adjacent to, a public institution or disability-specific housing complex, designed expressly around an individual's diagnosis that is geographically segregated from the larger community, as determined by the Secretary." (See "E. Setting" section on page 10740 of the Feb. 25, 2011 *Federal Register*.) Depending on how such language might be interpreted, it could exclude assisted living communities currently operating in proximity to institutional facilities, on a campus or otherwise, as well as assisted living units in Continuing Care Retirement Communities. Many seniors choose this campus model over freestanding models. The CMS proposed rule would deny this choice to low income seniors who rely on Medicaid. That's wrong.

NCAL believes that any definition of HCB settings should include all assisted living communities participating in Medicaid. Indeed, under the logic of the landmark Olmstead decision, depriving Medicaid beneficiaries of a major type of housing with services—assisted living—would be the opposite of a reasonable accommodation, especially for those seniors who prefer to live in assisted living and those for whom assisted living is the least institutional option available based on their clinical needs.

AHCA/NCAL also continues to have concerns regarding CMS' proposal to provide states with the option to combine or eliminate the existing three permitted waiver targeting groups. As we have noted in our comments on the proposed rules, combining target populations such as persons with mental illness with persons with developmental disabilities or frail seniors in waivers may increase the risk of inappropriate placement of vulnerable populations, as well as create safety issues.

Some Good News: Timely Implementation of Medicare Part D Co-Pay Legislation

NCAL, AHCA, and other national organizations recently commended CMS for deciding to implement Sec. 3309 of the Affordable Care Act on Jan. 1, 2012.[xi] The result of five years of advocacy by a coalition of national organizations, this legislation will eliminate cost sharing under the Medicare Part D prescription drug program for an estimated 600,000 dual eligible beneficiaries receiving HCB services, including those living in assisted living communities. Sec. 3309 will bring needed financial relief to this vulnerable group of very low-income seniors and people with disabilities and improve their medical care. It also will create parity in Part D cost sharing requirements between dual eligible beneficiaries in institutional and HCB settings. As noted in AHCA/NCAL's letter to CMS Administrator Donald Berwick, M.D., CMS opted for the earliest possible implementation date allowable for this provision under wording in the health reform statute. In a modest way, Sec. 3309 also may serve to ease financial pressure in some states, many of which have had to increase Medicaid beneficiaries' personal needs allowances so they can afford Part D medication co-payments.

Passage and implementation of Sec. 3309 provides a good example of how the larger assisted living community – including consumer advocates, providers, health professionals, state and federal agencies, and many other constituencies – can work together to gain the resources needed to improve the lives of the frail, elderly people that they all serve.

Improvements Needed To Expand Affordable Assisted Living

The recent dialogue and increased coordination between HHS and the U.S. Department of Housing and Urban Development (HUD) is a welcome development and holds great promise for expanding housing-with-services options available to low-income seniors and people with disabilities. However, while HUD recently made a number of housing vouchers available for non-elderly, low-income people to help them transition from institutional settings or remain in community settings, so far such vouchers have not been made available to elderly individuals. Lack of funding for housing also continues to be a major barrier to the transitioning individuals to community-based settings under the Money Follows the Person grant program.

Even though public money is currently scarce, it is imperative for policymakers to consider ways to help states cover the gaps in Medicaid funding. Policies that could be considered include making housing vouchers available to low-income assisted living residents including Medicaid

beneficiaries, providing increased public financing for construction of affordable assisted living, and expanding incentives and mechanisms for families to save for future long term care costs.

[i] More than two-thirds of the states use the licensure term "assisted living" and some states use a similar term (e.g., Tennessee uses "Assisted Care Living Facilities"). While the second most used term is "residential care," other state licensure terms include "boarding home, basic care facility, community residence, enriched housing program, home for the aged, personal care home, and shared housing establishment." Source: NCAL Assisted Living State Regulatory Review, 2011, National Center for Assisted Living, Washington, D.C., 2011.

[ii] This growth has been documented by both research done by the U.S. Department of Health and Human Services, which has published major reports on assisted living/residential care regulation and Medicaid policy in 2004 and 2007, and through NCAL's annual Assisted Living State Regulatory Review, which summarizes state regulations and analyzes regulatory changes and trends.

[iii] Analysis based on information collected for the National Center for Assisted Living (NCAL) *Assisted Living State Regulatory Review 2011*, NCAL, Washington, D.C. For additional information, please contact Karl Polzer, NCAL Senior Policy Director, at 202-898-6320 or kpolzer@ncal.org.

[iv] U.S. Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation, "Assisted Living and Residential Care Policy Compendium, 2007 Update," by Robert Mollica and Kristin Sims-Kastelein of the National Academy for State Health Policy.

[v] NCAL Regulatory Review, 2010 edition.

[vi] "Assisted Living and Residential Care Policy Compendium..."

[vii] U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, "Residential Care and Assisted Living: State Oversight Practices and State Information Available to Consumers," Robert Mollica, September 2006.

[viii] "Residential Care and Assisted Living: State Oversight Practices..."

[ix] *Governing* magazine, "Public Officials of the Year: 2007 Winner: Kevin Coughlin: Common-Sense Compliance," by Penelope Lemov, http://www.governing.com/poy/2007/coughlin.htm.

[x] "State Medicaid Reimbursement Policies and Practices in Assisted Living," Robert Mollica, National Center for Assisted Living, Washington, D.C., October 2009. Information for the report was obtained from two primary sources. Baseline information on state assisted living reimbursement policies and practices was obtained from previous studies sponsored by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Policy and Evaluation, and RTI International in 2002, 2004, and 2007. The information was updated through an electronic survey and telephone calls with state officials responsible for managing Medicaid services in licensed assisted living/residential care settings. Information was also obtained from state websites when available. Responses were received from 45 states and the District of Columbia. Information for states that did not

respond to the survey was obtained from previous reports and material found on state web sites. Data were collected between March and June 2009. To obtain a copy of the report, visit *www.NCAL.org*.

[xi] Federal Register, Medicare Program; Proposed Changes to the Medicare Advantage and the Medicare Prescription Drug Benefit Programs for Contract Year 2012 and Other Proposed Changes, Nov. 22, 2010, p. 71190.

Testimony prepared for the
Senate Special Committee on Aging
Hearing on
Ensuring Quality Oversight in Assisted Living
2:00 PM, November 2, 2011

Voices for Quality Care (LTC), Inc. (Voices) is a regional, non-profit, all-volunteer long-term care citizen advocacy organization of people who need long-term care services, their friends and families, resident and family councils, advocates, and concerned citizens working for quality long-term care services in all settings in Florida, Maine, Maryland, and Washington DC. We do not *speak for* the people who need long-term care services and their friends and families, we *are* the people who need long-term care and their friends and families. We appreciate the opportunity to submit testimony for the Senate Special Committee on Aging Hearing on Ensuring Quality Oversight in Assisted Living held November 2, 2011.

Voices runs a 24/7 helpline for people with long-term care issues. Because our (888) toll-free phone number is nationwide, and because it is featured on our web site, we receive calls for assistance from people in states other than the 4 in which we have volunteer members. We are constantly and continually in touch with what is happening "on the floors" and "in the beds" in long-term care situations. Our perspective is not one of in theory and from a distance. Our work is up close and in practice.

While a substantial amount of information was presented at this Hearing, one thing seemed to be missing. That was a definition of an ombudsman and a description of the critical nature of the Ombudsman Programs around the country. This is not surprising. This program, which has been with us since 1965, can often be described by the old cliché, "I have done so much with so little for so long that I can now do anything with nothing."

As advocates, there are two critical programs that we rely on for the provision of quality care and the enforcement of federal and state laws and regulations governing that care for people living in Assisted Living Facilities. Those are the Survey Agencies that operate under the Center for Medicare & Medicaid Services in the Department of Health and Human Services and the Long-Term Care Ombudsman Programs under the direction of the Administration on Aging. For us, the primary difference between these two agencies is that the Survey Agencies, while charged with enforcing laws and regulations, are present in long-term care facilities for just a few days during the annual surveys and on the occasions that a complaint has been filed and requires investigation. It can be as long as 3 months before a complaint lodged with a Survey Agency is

finally investigated. The Ombudsmen, on the other hand, are in the facilities on a regular basis, learn to know the individual residents, and respond to requests for assistance with issues that impact the daily lives of the residents but that are not necessarily addressed in law or regulation. Where the Survey Agencies are impartial, the Ombudsman are not.

Whereas the nursing homes and assisted living facilities have ample legal assistance and lobbyists looking out for their interests, the people living in these facilities and their families have few of these resources. What's more, they come into the long-term care system as novices with little understanding of their rights, what quality care looks like, or what they are entitled to. Without the help and guidance from a long-term care Ombudsman, they generally don't learn these critical bits of information until they no longer need them. Nor are many assisted living residents really able to advocate for themselves, particularly those who do not have strong families to back them up. While the survey and licensing agencies provide enforcement for federal and state regulations, it is the Ombudsmen who are in the facilities most often. It is the Ombudsmen who meet each resident and advocate for their care and quality of life needs.

The National Ombudsman Program was created by the Older American's Act in 1965 and has proven itself critical to the people who need long-term care and to those who advocate for them. This Program and this Act need considerably more funding, support, and respect than they currently receive, and far more support in carrying out their mission.

In the ten years Voices has been in existence, we've seen an intrusion of large publicly owned chains into what once was care provided by small stand-alone non-profit and individually owned for-profit assisted living facilities where those who own, run, and are responsible for the quality of care and quality of life they provide are both local and personally engaged in the daily operations of those facilities. We've also seen major changes in the way care is provided in these facilities. We see an increasing number of these homes now operated as a part of multistate or national private equity funds and REITs and run by large often publicly owned multi-state management companies with little or no connection, obligation, or visibility to the communities in which they own assisted living facilities. These chains are responsible only to Wall Street. Their bottom lines are not good care but good profits. The facility owners and managers are blessed with multiple lawyers, lobbyists, and ample funds for large campaign contributions.

The Ombudsman Programs are basically the only balance for the needs of the people who reside in assisted living facilities. Yet in our advocacy work for people who call in to our helpline for assistance, we are seeing a great variance in the efficiency and effectiveness of the various state and local ombudsman programs. We have not analyzed this phenomenon sufficiently to determine whether it is a result of the increasing political influence of these large chains and their Associations, or the fact that the Administration on Aging, in the past, has not sufficiently enforced the federal regulations governing the operations of the State and Local Long-Term Care Ombudsman Programs.

As an all-volunteer organization with extremely limited funds, we rely when and where we can on these government agencies to fairly and effectively deal with issues brought to us that fall within

their scope of work. Unfortunately, we are increasingly finding that the Ombudsman Programs particularly are not operating independently and according to their federal mandate as to act as resident advocates but are subject to considerable political manipulation. In some states we see seriously erratic differences from one local program to the next to the extent that the quality of the services received by a person contacting an Ombudsman will depend greatly on where in the state they reside. We are seeing this same erratic service across the country from state to state. We have seen the extreme results of political interference in the Florida Ombudsman Program this year. However, Florida is not the only state where political interference with Ombudsmen doing their duties is taking place. Most distressing to us is that we see very few Long-Term Care Ombudsman Programs either on the State or the Local levels that are in full compliance with federal law. We fear it may be very difficult to obtain first hand information on this issue from the Ombudsmen because their jobs are on the line. Very few Ombudsmen have the courage and determination of Brian Lee, former State Ombudsman of Florida, to do their job regardless of political interference.

The circumstances of people living in assisted living facilities were best described by a very honest politician who once told us, "You are advocating for a hidden population. Your people do not vote, they do not write letters to the editor, they do not call their legislators to complain, and what's more, they live behind closed doors. No one really remembers they are there." He was right in all but the voting part. "They" do vote and so do we who love them. We may not have funding for lobbyists. We may not have funding for large campaign contributions. We may not have the influence to operate behind the closed doors of Washington. But, we are Americans and the American Government is our Government. It is time to balance our needs with the needs of the providers.

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