

**SHOPPING FOR ASSISTED LIVING: WHAT
CUSTOMERS NEED TO MAKE THE BEST BUY**

HEARING
BEFORE THE
SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE
ONE HUNDRED SIXTH CONGRESS

FIRST SESSION

WASHINGTON, DC

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SHOPPING FOR ASSISTED LIVING: WHAT CUSTOMERS NEED TO MAKE THE BEST BUY

MONDAY, APRIL 26, 1999

UNITED STATES SENATE,
SPECIAL COMMITTEE ON AGING,
Washington, DC.

The committee met, pursuant to notice, at 1:02 p.m., in Room SD-106, Dirksen Senate Office Building, Hon. Charles E. Grassley, (Chairman of the Committee), presiding.

Present: Senators Grassley, Hagel, Hutchinson, Bunning, Breaux, Reid, Kohl, Wyden, Bayh, and Lincoln.

OPENING STATEMENT OF SENATOR CHARLES GRASSLEY, CHAIRMAN

The CHAIRMAN. I thank everybody for being here today and for the very large turnout. I appreciate the show of interest in this very important issue that the Senate Committee on Aging is considering today.

I particularly want to thank our witnesses from the government, the private sector, consumers and industry, and particularly the General Accounting Office, which did the work for our hearing today.

When some people hear the term "assisted living," the first question is, what is it? The industry is still so new that many consumers are not familiar with it or with the term. Despite the lack of widespread knowledge, assisted living as a form of care, as well as an industry, is growing very rapidly. Older Americans are moving into assisted living facilities every day. They see assisted living as a welcome alternative to nursing homes. They value the independence and the quality of life that assisted living can offer.

They are willing to pay out of their pockets for this type of residence and the service that goes with it. The average monthly base rate for assisted living is \$1,500. Additional fees can add up, as we will hear from our witnesses today.

Anecdotal reports suggest many satisfied customers, but it is difficult to move beyond anecdotal information and on to the hard facts. Assisted living means different things to different people and in different States. The 50 States have 25 different licensing categories for assisted living. Each state regulates it differently, making it a challenge to determine exactly how many people are in assisted living and what sort of services they receive.

By any estimate, the industry is big and it is getting bigger. Researchers report that 650,000 people live in 11,500 assisted living facilities. By comparison, 1.2 million people live in 17,000 nursing

homes throughout the United States. The assisted living industry predicts tremendous expansion. The industry reports it has 30,000 assisted living residences in operation now with 180,000 more expected within the next 10 years. An increasing number of States are directing some Medicaid money towards assisted living.

With this growth in mind, our committee asked the General Accounting Office to help us learn more about this industry. We asked the General Accounting Office to look at several aspects of assisted living: first, the residents' needs and the services provided; second, whether facilities give consumers adequate information in choosing a facility; third, different State approaches to oversight; fourth, the extent of quality of care problems; and last, the extent of consumer protection problems.

The motivation of this committee is to understand how assisted living can help meet our nation's skyrocketing long-term care needs. Long-term care is one of the most fundamental services any of us will require in life. It is also one of the most expensive. When we require it, we expect to get what we pay for. We hope and expect that it meets our needs.

Today's hearing will help us understand whether older Americans get what they pay for from assisted living and whether assisted living meets their needs. On the first panel, we will hear from two individuals who have had firsthand experience with assisted living through family members. Next, we will hear from the General Accounting Office's expert witnesses who have conducted this extensive research. Finally, we will hear from industry representatives.

I thank you all for being with us and now I call on our very cooperative ranking minority member, Senator Breaux from Louisiana.

[The prepared statement of Senator Grassley follows:]

PREPARED STATEMENT OF SENATOR CHUCK GRASSLEY

When some people hear the term "assisted living," their first question is, "What is it?" The industry is still so new that many consumers aren't familiar with it.

Despite the lack of widespread knowledge, assisted living is growing rapidly. Older Americans are moving into assisted living facilities every day. They see assisted living as a welcome alternative to nursing homes. They value the independence and the quality of life it can offer.

They're willing to pay out of pocket for these services. The average monthly base rate for assisted living is \$1,500. Additional fees can add up, as we'll hear from our witnesses today.

Anecdotal reports suggest many satisfied customers. But it is difficult to move beyond anecdotal information and on to hard facts.

Assisted living means different things to different people and in different states. The 50 states have 25 different licensing categories for assisted living. They all regulate it differently.

This variety makes it a challenge to determine exactly how many people are in assisted living and what sort of services they receive. By any estimate, the industry is big and getting bigger.

Researchers report that 650,000 people live in 11,500 assisted living facilities. By comparison, 1.2 million people live in 17,000 nursing homes.

The assisted living industry predicts tremendous expansion. The industry says it has 30,000 assisted living residences in operation now with 180,000 more expected within 10 years. An increasing number of states are directing some Medicaid money toward assisting living.

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- (1) the residents' needs and the services provided;

- (2) whether facilities give consumers adequate information to choose a facility;
- (3) state approaches to oversight;
- (4) the extent of quality of care problems;
- (5) and the extent of consumer protection problems.

Our motivation was to understand how assisted living can help meet our nation's skyrocketing long-term care needs.

Long-term care is one of the most fundamental services any of us will require in life. It is also one of the most expensive. When we require it, we expect to get what we pay for. We expect it to meet our needs. Today's hearing will help us understand whether older Americans get what they pay for from assisted living, and whether assisted living meets their needs. On the first panel, we will hear from two individuals who have had first-hand experience with assisted living through family members. Next, we will hear from the GAO. Then we will hear from expert witnesses who have conducted extensive research. Finally, we will hear from industry representatives.

STATEMENT OF SENATOR JOHN BREAUX

Senator BREAUX. Good afternoon, Mr. Chairman. Thank you very much. I doubt back in 1935, when Social Security was passed as a retirement program for our nation's seniors that anyone at that time would have predicted how all of this has evolved to where we find ourselves today. Terms like nursing homes and home health care and assisted living facilities were probably not in the minds of anyone who sat and drafted that very historic legislation.

But today, we are involved in all of these different endeavors as a means of improving the retirement years of our nation's senior citizens. And as these different types of industries dedicated to serving the nation's seniors spring up every day, it seems, it is getting more and more difficult for our nation's seniors and for their children and for people who care about them to really know all that is involved in delivering these types of services.

Assisted living facilities for the 21st century are very important. They are very important today. They will continue to be even more important in the future. How we pay for that extra care and assistance in our elders' golden years, is going to be a fundamental question. But also the quality of care in these new endeavors, how it is delivered, how it is supervised are going to be extremely important questions.

Today's hearing looks at a new type of facility that is currently unregulated by the Federal Government. That is not to say that it is any less of an industry or the quality of care is less than anything else that is regulated. The questions that are being asked and comments being made by the General Accounting Office with regard to assisted living facilities are very similar to the questions and the problems being associated with those facilities that are already regulated by the Federal Government, like nursing homes, as an example. Our concerns are the same for both industries.

Do they provide what they tell you they are going to provide? Do they follow the rules? Are they safe? Are they well run? Are they well managed? The same questions are important for those that are regulated by the Federal Government as well as those that are not regulated. My own State is beginning regulatory procedures for assisted living facilities. Pilot programs to pay for these types of facilities under the State Medicaid program are now being tested.

So I think it is important that we take a look at what is happening out there. It is increasingly, Mr. Chairman, obvious that when we talk about the retirement programs that we are not just talking

about a retirement check from Social Security. The availability of care and service delivery are important in retirement. Much more is involved. We have to find out, number one, is care being delivered adequately and properly. Two, how do we pay for this multitude of services. This hearing, hopefully, will address many of these concerns. I think that they are crucial to examine. Thank you very much.

[The prepared statement of Senator Breaux follows:]

PREPARED STATEMENT OF SENATOR JOHN BREAUX

Thank you all for joining us today to learn more about a new industry that could enable our elders to remain independent and institution-free. Assisted living has grown rapidly over the last decade because it offers an alternative to nursing homes. For individuals who need some assistance on a daily basis, but do not require a great amount of care, these facilities can offer a home away from home; a pleasant place to grow old. However, this industry—like many others—has some problems that must be examined. The General Accounting Office report released today will tell us just that. The study shows that 25 percent of the facilities surveyed in four states had five or more problems with quality of care or consumer protections. And while we don't know the national magnitude of the problems in assisted living facilities, we do know that things could be better. There is no excuse for poor care in these facilities. And whether the problems are isolated or pervasive, we must work together with the state regulators and the assisted living industry to solve them.

The trail that the assisted living industry blazes will set a precedent for other industries that will soon get into the "business of aging." Wall Street has already discovered that there are a myriad of new opportunities to be had as the population ages. Graying Baby Boomers will have money to spend on new products to meet their changing needs. Assisted living sprouted from this mentality, and other industries are sure to follow as the senior population swells. That is why it will become even more crucial for Congress, state governing bodies and local communities to watch out for the best interest of our seniors. New services and products can be exciting and useful, but they also can create a marketplace ripe for consumer abuse if not monitored carefully.

Thank you, Chairman Grassley, for holding today's hearing. I look forward to listening to the experts, consumers and industry representatives about their concerns. Thank you all for joining us, particularly Ms. Patricia Fleischmann Johnson and Ms. Collette Appolito, who have come to share their personal stories. All the testimony heard today will be tremendously useful to the Aging Committee, as we continue our efforts to protect America's elders.

The CHAIRMAN. I am going to call on our colleagues for a short summary of their presentation with a hope that some of their statements can be put in the record because we do have a long hearing today. I call on Senator Hutchinson first, and then Senator Wyden, then I will go back to the Senators that have come in on this side and then Senator Reid on that side.

STATEMENT OF SENATOR TIM HUTCHINSON

Senator HUTCHINSON. Thank you, Mr. Chairman. I also applaud you for calling the hearing today and for your leadership on all of these aging issues. I think today's hearing is especially timely.

The importance of our seniors being able to maintain a sense of independence, I think, is important and so the whole assisted living concept becomes very vital in ensuring that our senior citizens not only are able to the extent possible to maintain independence, but be well cared for and to live with dignity. So these kinds of facilities are becoming increasingly popular and the concept of aging in place, where your level of care intensifies as your needs grow, I think, is pretty justifiable.

The issue of regulation is one, I think, that it is good that we are having this hearing now, because this is the time to really address the relative roles of the State and Federal Government in regulating these kinds of facilities. The General Accounting Office report released today offers some very interesting insights that I think it is appropriate that we look into.

I look forward to hearing your testimony and we appreciate our panel coming today. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Wyden.

STATEMENT OF SENATOR RON WYDEN

Senator WYDEN. Thank you, Mr. Chairman. I want to commend you, Mr. Chairman, and Senator Breaux especially. I got interested in this issue with the General Accounting Office some more than three years ago, and the fact that you and Senator Breaux took such an interest in this issue has really made it now a topic of prime concern. I want to congratulate both you and Senator Breaux for your efforts.

Mr. Chairman and colleagues, this hearing is a real wake-up call. Good quality assisted living is an exciting option for the nation's older people, but frail and vulnerable seniors cannot be allowed to fall through the holes of the crazy quilt of regulation and inadequate oversight.

I spent the weekend at a good assisted living facility in Palo Alto, CA, where my mother resides. It is an excellent program. I had meals with the residents and it is a wonderful facility.

However, this report shows that not all of the facilities in this country are living up to those high standards. I am especially troubled by the evidence that the committee has accumulated indicating that seniors and their families are really kept in the dark all too often with respect to the major services that are covered by assisted living programs. I would quote just very briefly, Mr. Chairman, at the bottom of page 15 of the report with respect to the contracts at these facilities.

It states, "The written materials that were reviewed rarely mention staffing, medication policies, or grievance procedures. Only one in three contain information about services not covered or not available." I think it is absolutely unacceptable that seniors and their families are kept in the dark in these instances documented by the evidence that is being released today.

Finally, Mr. Chairman, it seems especially important that steps be taken now to make sure that low-income older people are able to secure the services of assisted living programs. We note that many of these programs do cover the more affluent older people, but a big challenge, as documented by this report, is to make sure that lower-income elderly are covered.

But at the end of the day, this committee has a chance to avoid a lot of the mistakes that were made with respect to the development of Medicare and Medicaid. Now, where we have Federal involvement, State involvement, and local involvement, rather than producing an arrangement that wastes resources and produces a lot of duplication, we have a chance on a bipartisan basis to do the job right.

So I look forward to working closely with you, Mr. Chairman. As I can tell you from my experiences this weekend, there is good quality assisted living in this country. Now we have to take steps to bring all of the facilities up to those standards and I look forward to working with you and our colleagues.

The CHAIRMAN. Thank you, Senator Wyden.

Senator Bunning, and then Senator Reid.

STATEMENT OF SENATOR JIM BUNNING

Senator Bunning. Mr. Chairman, I would like my full statement to be put into the record and I will just say that this GAO report is all encompassing. We must be prepared to take care and investigate those assisted living facilities that are not living up to standard and we must be able to assure our seniors that they are getting the best quality care that they can get when they go to assisted living quarters.

I am anxious to hear our witnesses today and I am looking forward to the testimony. Thank you.

The CHAIRMAN. Thank you.

Senator Reid.

STATEMENT OF SENATOR HARRY REID

Senator REID. Mr. Chairman, while the assisted living industry is booming nationwide, what is going on in Nevada is virtually impossible to track. Residential facilities for groups in Nevada, we are adding an additional one every week. It is very difficult to monitor and to regulate those, as indicated from a story that appeared in the newspapers out of Reno last week.

A 74-year-old man climbed through his window in a facility that was licensed to care for the elderly in need of limited supervision. This man wandered for a while before he fell in a ditch. Actually, it was a sanitation district plant, and his body floated several miles before it was caught in one of the grates.

Like so many Americans, this man suffered from Alzheimer's. He was living in a group home that was not licensed to take care of people in his condition. While I am not totally familiar with all the facts of the case—my office is working on that now—this particular incident shows that there are tragic stories that occur every day and it is important for consumers to have access to information as to what kind of facility they are placing their loved one in.

I think it is very important that these facilities be monitored and have Federal standards. We cannot have one standard in Louisiana, one in Kentucky, one in Oregon, one in Nevada, and one in Iowa. We have to have, I think, a national standard for this assisted living. By the year 2030, there will be 70 million seniors living in this country and we have to be prepared for the seniors that will be living in this country.

Mr. Chairman, I ask unanimous consent that my full statement be made part of the record.

The CHAIRMAN. It will be, Senator Reid.

[The prepared statement of Senator Reid follows:]

PREPARED STATEMENT OF SENATOR HARRY REID

Good afternoon Mr. Chairman, members of the Committee and distinguished guests. I am pleased that the Committee is devoting this hearing to the quality of care and consumer protections in assisted living facilities.

While the assisted living industry is booming nationwide, it is virtually impossible to keep track of the growth and construction of assisted living facilities in my home state of Nevada. Nevadans are increasingly turning towards assisted living as a welcome alternative to nursing homes. Many families and residents are attracted to the assisted living philosophy that fosters independence and dignity. However, with the rapid growth of the assisted living industry comes numerous challenges and questions that I hope we will be able to address today.

For a family looking to place a loved one in an assisted living facility, the growing number of options stemming from an increasingly competitive market can make this search seem overwhelming. Consumers need clear and complete information about the types and quality of services provided in various assisted living facilities. If residents and families do not have access to such information, they run the risk of placement in a facility that cannot provide necessary and often vital care and protections.

Mr. Chairman, just last week, a 74 year old man from Reno climbed through his window in a facility that was licensed to care for elderly people in need of limited supervision. This man wandered for a while before falling into a ditch. His body floated several miles before it was caught in a grate at a water plant.

Like so many Americans, this man suffered from Alzheimer's disease. However, he was living in a group home that was not licensed to care for people in his condition. While I am not familiar with the details surrounding this particular incident, this tragic story shows how important it is for consumers to have access to the information that enables them to make informed choices about a facility's ability to provide necessary care.

The rapid growth of the assisted living industry gives rise to another important concern—a shortage of trained and qualified employees. In Nevada, many fear that there are not enough trained professionals available to keep pace with rapid construction of assisted living facilities. Facilities with insufficient, unqualified or untrained staff will not be able to meet the needs of the vulnerable population they serve.

By the year 2030, there will be 70 million seniors living in this country. As our nation seeks ways to care for an aging population, we must work to ensure that living a long life also means enjoying a high quality of life. Assisted living is one approach that will enable many seniors to enjoy their golden years. I look forward to learning more about assisted living facilities and working to address some of the challenges facing this industry.

The CHAIRMAN. Senator Hagel.

STATEMENT OF SENATOR CHUCK HAGEL

Senator HAGEL. Mr. Chairman, thank you. I, too, wish to welcome our witnesses and thank each of them for the contributions they are making not only today but every day. We are grateful and we are a better country.

I do have a statement, Mr. Chairman, that I will submit for the record and look forward to hearing the witnesses. Thank you.

The CHAIRMAN. Thank you, Senator Hagel. I appreciate that very much.

[The prepared statement of Senator Hagel follows:]

PREPARED STATEMENT OF SENATOR CHUCK HAGEL

Good afternoon, Mr. Chairman. Thank you for calling this timely and important hearing.

As America's baby boomers move into retirement, long-term health care will play a very important role in providing services to meet their needs. As part of the effort to create viable long-term care options, assisted living services will play a crucial role. Assisted living services allow the residents to maintain choice and independence while offering personal assistance and supervised health care.

Today, there are nearly 30,000 assisted living facilities in the United States with over 1.15 million residents. Nebraska has over 140 facilities with a total of 6000

beds designated for assisted living. By the year 2025, the number of Americans in assisted living facilities is estimated to grow to more than 2.1 million, nearly a 70% increase.

We should encourage the continued development and growth of assisted living services. However, we must ensure that the quality of care provided by these services is the best available. Additionally, it is important that there is sufficient information available to residents and potential residents about the services provided through assisted living.

Currently, states are primarily responsible for oversight of assisted living facilities. The Social Security Administration and the Health Care Financing Administration (HCFA) do have some responsibilities for consumer protection and quality of care issues, but for the most part, the states are responsible. The state should have the responsibility of regulating assisted living facilities. However, the states need to ensure that residents of these facilities receive the highest quality of service. In 1997, the State of Nebraska passed legislation identifying assisted living as a recognized program and set guidelines relating to the services provided.

I realize that there has not been much research done on assisted living in the past, so it is difficult to determine exactly what is happening in the area of assisted living regulation. I hope that today's release of the General Accounting Office's (GAO) report on assisted living will help shed some light on this important subject.

I look forward to hearing from the panelists today on their thoughts on assisted living services and what must be done to ensure quality service. Additionally, I look forward to the findings contained in the GAO report.

Thank you, Mr. Chairman.

The CHAIRMAN. Just before we go to witnesses and I introduce them, I would like to correct something that I said both today as well as in a previous news conference, and that is when I refer to the General Accounting Office report saying that 25 percent of the facilities provide consumers with contracts, that is correct, but I should add to that that 68 percent have provided contracts upon request.

I am very pleased to welcome both witnesses of our first panel, Patty Johnson and Collette Appolito. Both of them join us today to share their personal experiences shopping for an assisted living facility for a family member. Ms. Johnson will share her experiences in overseeing her father's care in a Florida facility and Ms. Appolito will share her experiences overseeing her mother's care in an Ohio assisted living facility.

We greatly appreciate your willingness to travel this far to share your experiences. I will start with Ms. Johnson and then Ms. Appolito, and then after both of you have finished, then we will have questions from the Senators. Would you proceed, please?

**STATEMENT OF PATRICIA FLEISCHMANN JOHNSON, LARGO,
FL**

Ms. JOHNSON. Thank you for having me here. My name is Patricia Fleischmann Johnson. I am the daughter of Albert Fleischmann, who lives in an assisted living facility in Pinellas County, FL. My dad is 85 years old. He retired from the Board of Directors of Ace Hardware. He sold all seven of his hardware stores. He is a former board member of the St. Petersburg Yacht Club and a member of the Gulf Marine Hall of Fame. He moved into an assisted living facility in 1997 after having an aneurysm repaired.

I am, by profession, the President of Adult Comprehensive Protection Services, Incorporated, a charity that serves the Sixth Judicial Circuit of Florida. We serve 256 wards of the court, and of those wards, presently 134 live in assisted living facilities. I have

served the elderly and persons with disabilities for more than 20 years in various capacities. My formal comments will be directed to you as Mr. Fleischmann's daughter, but I will be open to comments and questions on others that I serve as guardian.

On January 16 of this year, 1999, my father walked from his villa to the dining room for breakfast. This is a nice five-minute walk for him. He did not feel well and put his head down on the table when he arrived. He told the staff that he was too ill to eat. They did not respond. Rather than help Dad to their extended care facility on the grounds, the staff let him walk back to his villa alone. He immediately called me at home, whereupon I went to him. I found him gray in color and took him to the closest emergency room. The doctor told me that Dad had experienced a heart attack that morning. He had a second heart attack in the emergency room.

It was a long day. However, at about 6:00 that evening, I went home to change and got ready to return to the hospital intensive care unit. I noticed that my beeper had never gone off. There were no messages on my phone. I called the facility and told them that I had not gotten to visit with my father during the day and wanted to know whether he was okay and if he had eaten his dinner. The staff member that answered the phone told me he was just fine. Of course, I was very upset and I did tell the staff member that she was wrong.

Before Dad returned to the assisted living facility, I met with the administrator. She increased his level of care, charging him an additional \$400 a month for the additional services, which is fine. This meant that he was going to go to the nursing station two times a day for his medication and blood pressure check and they would check on him every two hours in his villa and encourage him to drink fluids. Within 13 days, I called the physician to tell him that Dad looked really bad to me. The doctor sent his assistant to the ALF. When she saw Dad, she immediately had him readmitted to the hospital for dehydration.

To summarize the problems we have experienced, they did not attend to Dad when he did not feel well. At best, the staff member did not both to check on Dad's condition, and at worst, she just lied. They did not help him keep his fluid intake to an adequate level. They did not recognize that he was dehydrated and needed hospitalization.

I do not want to leave here without acknowledging the needs of my 134 wards that live in ALFs in Pinellas County. I have wards that have spent all their money at a facility, only to be asked to move when the funds are gone. They are then forced to move into a facility that accepts the inadequate \$22 per day that the State of Florida pays to care for them. The food is terrible. The supervision is inadequate. There is no care to speak of. An attorney that I work with recently referred to one of these facilities as a "filthy house of horrors."

Finally, I want to be clear that Dad wants to stay with the friends that he has made at the ALF, as this represents his independence. Dad and I both want the care to be better and hope that the quality of care will improve for elders that we love.

I am honored to have the opportunity to appear before you today.
Thank you.

[The prepared statement of Ms. Johnson follows:]

Statement by
Patricia Fleischmann Johnson
April 26, 1999

My name is Patricia Fleischmann Johnson and I am the daughter of Albert Fleischmann, who resides in an Assisted Living Facility, (ALF) in Pinellas County Florida. Dad is 85 years old, retired from the Board of Directors of ACE Hardware, has sold all seven of his hardware stores. He is a former board member of the St. Petersburg Yacht Club, and member of the Gulf Marine Hall of Fame. Dad moved into an ALF in 1997, after having an aneurysm repaired.

I am by profession, the President of Adult Comprehensive Protection Services, Inc., a charity that serves the Sixth Judicial Circuit of Florida. We serve 256 wards of the court, and of those wards, presently 134 live in ALF's. I have served the elderly and persons with disabilities for more than 20 years in various capacities. My formal comments will be directed to you as Mr. Fleischmann's daughter, but I will be open to comments and questions on others that I serve s Guardian.

On January 16, 1999, my father walked from his villa to the dining room. This is a nice five minute walk for him. He did not feel well and put his head down on the table. He told the staff that he was too ill to eat. They did not respond. Rather than help Dad to their Extended Care Facility on the grounds, the staff let him walk back to his villa alone. He immediately called me at home, whereupon I went to him, found him gray in color, and took him to the closest emergency room. The Doctor told me that dad had experienced a heart attack that morning. He had a second heart attack in the emergency room.

It was a long day,, however, at about 6:00 p.m. that same evening I went home to change and get ready to return to the hospital intensive care unit. I noticed that my beeper had never gone off, and that there were no messages on my phone. I called the facility and told them that I had not gotten to visit with my father during the day, and wanted to know whether he was OK, and asked if he had eaten his dinner. The staff member told me HE WAS JUST FINE. Of course I was very upset and did tell the staff member that she was wrong.

Before Dad returned to the ALF, I met with the administrator. She increased his level of care, charging him an additional \$400.00 a month. This meant that he was to go to the nurses station two times a day for his medication and blood pressure check, and they would check on him every two hours in his villa, and encourage him to drink fluids. Within 13 days I called the physician to tell him that Dad looked really bad to me. The Doctor sent his physician assistant to the ALF. When she saw Dad, she immediately had him readmitted to the hospital for dehydration.

To summarize the problems we have experienced:

They did not attend to Dad when he said he did not feel well.

At best the staff member did not bother to check on Dad's condition, and at worst, just lied.

They did not help him keep his fluid to an adequate level.

They did not recognize that he was dehydrated and needed hospitalization.

I don't want to leave here without acknowledging the needs of my 134 wards that live in ALF's in Pinellas County Florida. I have had wards that have spent all of their money at a facility, only to be asked to move when the funds are gone. They are then forced to move into a facility that accept the inadequate \$22.00 per

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Finally, I want to be clear that Dad wants to stay with the friends he has made at the ALF, as this represents his independence. Dad and I both want the care to be better, and hope that the quality of care will improve for the elders we all love. I am honored to have had the opportunity to appear before you today.

The CHAIRMAN. Thank you, Ms. Johnson.
Ms. Appolito.

STATEMENT OF COLLETTE APPOLITO, CLEVELAND, OH

Ms. APPOLITO. Thank you, Mr. Chairman and the rest of the committee. My name is Collette Appolito and my experience with Alzheimer's disease began in the spring of 1996, when it became evident that my mother, who was 61 years old at the time, was having memory challenges.

My mother's best friend called me from San Diego, CA, where my mother lived, to tell me my mother's memory was getting worse. My mother was forgetting how to get around in a city in which she lived for over 30 years. For at least three years prior to this, I can remember my mother would ask for my phone number. She would repeat things. My brothers and my sister made the same observation.

In August 1996, my mother's doctor diagnosed her with severe dementia. After returning from the doctor's office, we found my mother's phone was disconnected for nonpayment and she was served with an eviction notice.

At this point, my siblings and I were faced with deciding where to move Mom. We no longer lived in San Diego. We all researched the possibilities of long-term care in our respective cities. At that time, if there were assisted living facilities available, my mother's finances would not afford her the opportunity to reside in one.

I looked at a nursing home in the San Diego area and determined my mother was not ready for nursing care. She needed a secure environment to make sure that she did not wander off and not remember how to get back, as well as make sure that she was eating balanced meals. My mother was still very aware of her surroundings and her greatest fear was that she would end up in a nursing home.

I returned to Cleveland and found that there were not many options for someone in the beginning stages of Alzheimer's disease, someone who may require some prompting, a secure environment, the ability to socialize with others in the same or similar condition, and for someone on a limited income. At this point, due to my mother's income, the level of care provided, necessity for a secure environment, and the potential for my mother to live with other residents at her level, I chose to move her in October 1996 to R&R Elder Care, a group or boarding care home in Brunswick, OH. My mother was aware of the fact that we moved her and she was very angry and upset. I think on some level, she knew the move was in her best interest, but she was always a very independent woman and had a difficult time giving up her independence. This was a distressing time, as well as disturbing move, for all of us.

At the time, I lived in a suburb of Cleveland called Westlake and I noticed a new Alzheimer's assisted living facility was to open in early 1997. The concept of this facility sounded wonderful. I was told there would be two caregivers in each house for the first and second shifts as well as an LPN on duty from 8:30 in the morning until 8:30 at night.

Prior to the move-in, the wellness director would assess my mother and determine her exact needs, and the level of care would

determine the monthly rate. The five levels of care, along with the monthly rate, were provided in the brochure. What I did not know at the time was how the level of care was determined. The marketing director explained the level of care was determined by my mother's needs, but until the assessment, I would not know exactly how much assistance my mother would need and the cost associated with the care.

In August 1997, I found that my mother was physically abused by a caregiver at the group home. I was mortified. A few weeks prior to the incident, my mother received a sum of money that would allow her to move into the assisted living facility in Westlake. I was happy because my mother was able to move into a beautiful new facility. She was happy, as well. She happened to bond with a resident in a similar condition and the two became inseparable.

I became frustrated at times with Arden Courts. I would stop by after work or in the evening and I could not find a caregiver in her house. If the caregiver had to provide one-on-one assistance for another resident, there was no one else available. This was contrary to what I was told. The facility apparently was not prepared for call-offs or terminations. They said that they were having difficulty hiring staff.

In January 1998, I entered my mother's cold room and determined the heater was not working. The heater was not repaired for one complete week. They tell me they asked my mother to sleep in another room, but she refused. This did not surprise me because my mother was often confused in the facility itself due to the colors in each house. She would go to another room and would not recognize it and so she was confused because she was told that was not her room, and it was not, but she did not understand that. She depended on others, mainly me, to speak for her, and I paid the facility to take care of her when I was not there.

In August 1998, a change in the service level was necessary. This was explained to me and we reviewed my mother's needs and the monthly cost of the new service level. The next bill I received indicated there was an adjustment, but there was no justification or reason. I asked the business manager for an explanation; she said she would look into it. I never received a response.

Twice a year, the facility would invite family members to come in and participate in a focus group. In September or October of last year, nine family members met with the vice president of Operations and identified the following major concerns: housekeeping, lack of adequate caregivers, and missing personal items. We were told that per the staffing models provided by Manor Care, there was adequate staff.

In November 1998, I was called by the wellness director and was told my mother was losing weight. She lost approximately five to six pounds in three weeks. She needed assistance with feeding, and more than just prompting. I did observe that if there were one caregiver in the house, the caregiver would have to feed 12 or 13 residents. By the time the caregiver was done preparing and serving the residents their meals, the caregiver might have to prompt a resident to eat, get more of a beverage, serve another plate of

food, and clean up. That is quite a bit for one caregiver to do for 12 to 13 residents.

My mother is now 64 years old and lives in a nursing home. I moved her in February of this year. She still does not eat much, but the assistance is there and she is given as much time as necessary to eat what she wants.

In summary, my mother lived in two different assisted living facilities for a total of about 30 months and we wrestled with the following issues. Assisted living is expensive and not available to those of modest means. It was difficult to predict the expected cost of this care because it is dependent upon assessment of need, which can change frequently for an Alzheimer's patient. The level of care was inadequate because of a shortage of care professionals. One caregiver frequently had to feed a dozen residents, which allows no assistance to those with dementia. The level of maintenance support was insufficient. It took a week to repair a heater. The concept of assisted living care is wonderful. The reality of it for a middle-income person with dementia is far from perfect.

[The prepared statement of Ms. Appolito follows:]

**Testimony of
Collette Appollito
April 26, 1999**

My experience with Alzheimer's disease began in the spring of 1996 when it became evident that my mother, who was 61 years old at the time, was having memory challenges. My mother's best friend called me from San Diego, California, where my mother lived, to tell me my mother's memory was getting worse. My mother was forgetting how to get around in a City in which she lived for over 30 years. For at least three years prior to this, I can remember my mother would ask for my phone number (my brothers and sister made the same observation). In August of 1996 my mother's doctor diagnosed her with 'Severe Dementia'. After returning from the doctor's office, we found my mother's phone was disconnected for non-payment and that she was served with an eviction notice.

At this point my siblings and I were faced with deciding where to move Mom. We no longer lived in San Diego. We researched the possibilities of long term care facilities available in our respective cities. At that time, if there were assisted living facilities available my mother's finances would not afford her the opportunity to reside in one. I looked at a nursing home in the San Diego area and determined my mother was not ready for nursing care. My mother needed a secure environment, to ensure that she did not wander off and not remember how to get back home as well as make sure she was eating balanced meals. My mother was still aware of her surroundings and her greatest fear was that she would end up in a nursing home.

I returned to Cleveland and found that there were not many options for someone in the beginning stages of the disease, who may require some prompting, a secure environment and the ability to socialize with others in the same or similar condition. At this point, due to my mother's income, the level of care proved, necessity for a secure environment and the potential for my mother to live with other residents at her level, I chose to move her in October of 1996 to R & R ElderCare, a group home in Brunswick, Ohio. My mother was aware of the fact that we moved her and was very angry and upset. I think on some level she knew the move was in her best interest, but she was a very independent woman and had a difficult time giving up her independence. This was a distressing time as well as a disturbing move for all of us.

At the time I lived in Westlake, Ohio (a suburb of Cleveland) and noticed a new Alzheimer's Assisted Living Facility, Arden Courts, was scheduled to open in Westlake early in 1997. The concept of the facility sounded wonderful. I was told there would be two caregivers in each house for first and second shifts, as well as a LPN on duty from 8:30 a.m. to 8:30 p.m. Prior to move-in, the Wellness Director would assess my mother to determine her exact needs and the level of care would determine the monthly rate. The five levels of care along with the monthly rate were in the brochure. What I did not know was how the level of care was determined. The marketing director explained the level of care was determined by my mother's needs, but until the assessment I would not know exactly how much assistance my mother would need and the cost associated with the care.

In August of 1997, I found that my mother was physically abused by a caregiver at the group home. I was mortified. A few weeks prior to this incident, my mother received a sum of money that would allow her to move into ArdenCourts. My mother was able to live in a beautiful new facility and I was confident she would receive good care. Overall, I was very pleased with my mother's stay at Arden Courts. She was happy. She bonded with another female resident and the two became inseparable. That was comforting to me to know my mother had someone else to spend time with.

I became frustrated at times with Arden Courts when I would stop by after work or in the evening and I could not find a caregiver for her house. If the caregiver had to provide one on one assistance for another

resident, there was no one else available. This was contrary to what I was told. The facility apparently was not prepared for call-offs or a termination; they said they were having difficulty hiring staff. In January of 1998, I entered my mother's cold room and determined the heater was not working. The heater was not repaired for one complete week. They tell me, they asked my mother to sleep in another room but she refused. This did not surprise me since she was confused about the colors of the houses and frequently went to the same room in another house and thought it was her room. This was aggravating for my mother because she often entered another resident's room and was told she was in the wrong room. The fact that it took one week to repair a heating unit in the middle of winter was unacceptable. My mother did not have the ability to tell staff that her room was cold. She depended on others (mainly me) to speak for her. I paid the facility to take care of my mother while I was not there.

In August of 1998, a change in the service level was necessary. This was explained to me and we reviewed my mother's needs and the monthly cost of the new service level. The next bill I received indicated there was an adjustment but there was no justification or reason. I asked the business manager for an explanation, she said she would look into it. I never received a response.

I believe twice a year, Arden Courts invites family members to participate in a focus group. In September or October of 1998, nine family members met with the Vice President of Operations and identified the following major concerns: housekeeping, lack of adequate caregivers, and missing personal items. We were told that per the staffing models provided by Manor Care, there was adequate staff.

In November of 1998, I was called by the wellness director and was told my mother was losing weight, she lost approximately five to six pounds in three weeks. She needed assistance with feeding (more than just prompting). I did observe that if there were one caregiver in the house she or he would have twelve to thirteen residents to feed. By the time she or he was done with preparing and giving the residents their meals, she or he might have to prompt a resident to eat, get more of a beverage, etc.

My mother is now 64 years old and lives in a nursing home. I moved her in February of this year. She still does not eat much but the assistance is there and she is given, as much time as necessary to eat whatever she wants to eat.

In summary, my mother lived in two different assisted living for a total of 30 months and we wrestled with the following issues:

- 1) Assisted living is expensive and not available to those of modest means.
- 2) It was difficult to predict the expected cost of this care, because it is dependent upon an assessment of need, which can change frequently for an Alzheimer patient.
- 3) When service levels did increase, it was not clear as to why and what additional care was being provided.
- 4) The level of care was inadequate because of a shortage of paraprofessionals; one caregiver frequently had to feed a dozen residents, which allowed no assistance to those with dementia.
- 5) The level of maintenance support was insufficient; it took a week to repair a heater.

The concept of assisted living care is wonderful; the reality of it for a middle income person with dementia is far from perfect.

The CHAIRMAN. Thank you very much, Ms. Appolito.

I will start the questioning and we will have five minutes for each member. The changes that go along with finding long-term care for family members, obviously, as you explained, can be very difficult, especially when it requires someone to move from their home. Can you start by telling us when you first learned about assisted living and what it could offer, and how did you go about shopping for assisted living facilities? Last, how did you decide that assisted living was the right thing for your family member? We will start with you, Ms. Johnson.

Ms. JOHNSON. As a professional, I have been working with assisted living facilities for a good 15 years, so I had visited with quite a few of them. In the area in which I lived, there are well over 200 assisted living facilities and they go from State rate at \$22 a day all the way up to \$150 a day.

The reason that I decided, or Dad and I actually decided that Dad needed to live in an assisted living facility was because he could not take care of himself at home any longer and he needed a small amount of assistance. He was living at my home recovering from the aneurysm surgery and he wanted his independence and his peer group and he needed the socialization skills. So we set about looking for which place he liked the best. Luckily, it was very, very close to my home, as in minutes. I can actually ride my bike from my home to the facility, and do quite often. I also have wards of the court that live at that facility and have been familiar with it since it opened. So I kind of have a little heads up on family members that would be going through the same problem.

Senator REID. Mr. Chairman, could I interrupt and ask your permission to submit some questions in writing to the witnesses?

The CHAIRMAN. Yes. If you need to ask a question, I will stop. Senator REID. No.

The CHAIRMAN. That reminds me, too. He will submit some questions to you to answer in writing. Could we have those back in two weeks?

Ms. JOHNSON. Yes.

Ms. APPOLITO. Yes.

The CHAIRMAN. Thank you very much.

Ms. Appolito.

Ms. APPOLITO. At the first sign of crisis, I leaned on several different, I guess, government agencies in Southern California for assistance in helping me determine what would be the option. At that point, I knew nursing care would not work because my mother was too aware at the time and she would not have allowed us to move her into a nursing home. So I was able to research through the Alzheimer's Association and other agencies available.

I decided, I guess, assisted living was right for my mother because nursing care was not the answer. When I did tour the facilities, I felt that it was a little too much like a hospital setting and that the residents were too far beyond my mother's comprehension and that she would not survive in that type of setting.

The CHAIRMAN. Once you did decide on a residence, did you feel well informed about the facility's services? What materials or resources, if any, did you rely on to help answer those questions? Did you spend much time reviewing the residence agreement?

Ms. JOHNSON. Again, because this is my profession and I have used that facility for many years, I did know what the contract was. I have reviewed it and gone over it for many years.

Do I feel it is adequate? No, I do not feel that it is adequate. I think that it does not answer questions. There are great big voids in that contract that can be—you could almost fall in them. But the contracts are industry-oriented. They are slanted toward the side of the facility, not toward the side of the consumer, and many of the people where I live, where I work, where my father is, are seniors that do not have someone. They do not have family. They do not have someone helping them. They are at the mercy of whatever the industry says and they are at that mercy for as long as the contract lasts.

The CHAIRMAN. Ms. Appolito.

Ms. APPOLITO. The information that I had basically were marketing brochures and talking with the staff, such as the wellness director, the marketing director, and the executive director. I would agree with Ms. Johnson that the information that is provided is inadequate and is slanted towards the facility.

The CHAIRMAN. Senator Breaux.

Senator BREAU. Thank you, Mr. Chairman. I thank our witnesses for their testimony. It has been, I think, very helpful. Senator Wyden and I were just talking about our own situations with our families. We can really appreciate your concerns.

If we think we have problems now, just look down the road to the 77 million more baby boomers who are going to be entering into their golden years in the not-too-distant future. Starting in the year 2008, 77 million more people are going to become eligible because they will start to turn 65. We are a nation that is living a lot longer than we used to, and that is the good news. It is also the bad news, because we have to ask ourselves: how do we take care of this large volume of new people coming into the system? These are terrific challenges.

I think that one of the things that keeps occurring in all of the hearings we hold on long-term care is that we need adequate information for people to make adequate choices. My wife and I were in a hardware store yesterday trying to decide on a microwave. We did not know which one to buy. I said, well, let's go look at Consumer Reports and we will get all the information we need on the microwaves, which ones break early, how much it will cost to fix them, which ones give the right service.

But in the area of health care, we do not have anything like that. You do not have a book that you can go through and look at assisted living facilities to learn about the ones that have been put on probation or those that have had their licenses yanked or anything like that.

We give more information to consumers on toasters and microwaves and washing machines than we give them on something as important as assisted living, nursing homes or any of the services that are available to the nation's seniors. They need the good information to make the right choices. Bad information leads to bad choices.

My state of Louisiana now has a law that would, Ms. Appolito, require any assisted living facility that advertises as offering spe-

cial care for Alzheimer's patients actually list what they do that makes them particularly qualified to give care to these residents. I take it that the facility that you were looking at did not have that type of information?

Ms. APPOLITO. Dealing specifically with Alzheimer's?

Senator BREAUX. Yes.

Ms. APPOLITO. They did.

Senator BREAUX. They did?

Ms. APPOLITO. They marketed themselves as a facility for residents with Alzheimer's disease.

Senator BREAUX. Did they spell out in their marketing materials the type of services that they were supposed to provide? Did they actually provide those services to their residents?

Ms. APPOLITO. They did spell out the services that they were going to provide. I would not say on—overall, I was very satisfied. There were many of us that were very concerned about the care that was provided, that the caregivers were not properly trained. The caregivers were providing the one-on-one assistance and were there with our loved ones 24 hours a day. It was unacceptable to me to walk into a room that is ice cold in the middle of winter and no one in that facility ever said anything about it. No one knew. And then the heater went unrepaired for one complete week.

Senator BREAUX. I am sorry about the problems you both experienced. It is not acceptable, to say the least. But I am also struck by the fact that when we had hearings not too long ago on nursing homes, which are federally regulated because of the Medicare program, that the problems we heard then were similar to these problems. Here are facilities that are regulated only by the States. Yet, the problems are the same. The consumer concerns are the same for both; one that is regulated by the Federal Government and one that is not regulated by the Federal Government.

Clearly what is needed is more than just us passing another set of laws. I mean, we could have the same laws that we have for nursing homes apply to assisted living facilities, and the situation could remain the same. I am concerned that Federal regulation would not necessarily solve the problems. This situation requires more than just passing more rules and regulations.

But I think standards are important. These facilities have to know that when they say they are going to provide a certain type of service, that they must provide it. There must be appropriate and proper penalties if they do not meet the standards that they espouse to and which we all expect them to meet. This is a real challenge and there are not any easy answers out there. Thank you.

The CHAIRMAN. Senator Hutchinson.

Senator HUTCHINSON. I really would associate myself with the comments of Senator BreauX, and particularly not only his comments on regulation and how they should be regulated and that that is not always the answer, that there are much bigger problems there, but also in the need for information in making those choices.

My mom, we did not put her in an assisted living facility or a nursing home, but we were looking at someone that we could bring in to stay with her during the day hours when she was alone, and then at night, we would be there as her family. But we faced the

same kind of difficulty in getting information about the various companies that had in-home health care and nursing, in finding background checks, in finding their qualifications and their experience. You are just taking a big chance. You do not always know. I know that is the same experience you found in using these facilities. Ms. Appolito, the facility, it specialized in Alzheimer's care, is that correct?

Ms. APPOLITO. Yes, it did.

Senator HUTCHINSON. Would you say that your mother's condition was similar to those of other residents, was comparable to?

Ms. APPOLITO. Yes, it was.

Senator HUTCHINSON. Did the wellness director ever talk to you about what to expect in the way of changes in your mother's condition?

Ms. APPOLITO. We talked a little bit about that. I was also aware, based on my association with the Alzheimer's Association. So I had some knowledge of it from outside, as well. So I was a little bit probably more informed when I went in looking.

Senator HUTCHINSON. Are you aware as to whether family members of other residents had that same kind of support group and same kind of information available to them?

Ms. APPOLITO. I think that they did. I could not say for sure, but I would think that they did.

Senator HUTCHINSON. If I understand your testimony, when the assisted living facility, they approached you after about a year after your mother's admission and discussed transferring your mother?

Ms. APPOLITO. Yes.

Senator HUTCHINSON. What reasons did they give at that time?

Ms. APPOLITO. Because she needed more assistance with feeding. It was no longer just a prompting issue. She needed someone to cut her food and to probably help her eat it and to sit there and kind of coach her along. With one or two caregivers for 13 residents, they did not have the staff to support her in that way, although they did increase the service level and I was paying for it when I left there and I am now paying at the nursing home where she lives less than I was paying that assisted living facility.

Senator HUTCHINSON. So her health had declined to the point that they were unable to provide the kind of care she needed?

Ms. APPOLITO. Right.

Senator HUTCHINSON. The cost increase was pretty dramatic in that one year. It increased to about \$1,700 a month?

Ms. APPOLITO. Yes, it did.

Senator HUTCHINSON. That is very dramatic. Were you able to find out what they were providing in additional services to justify that dramatic increase?

Ms. APPOLITO. Yes. Quarterly, they did provide a care assessment meeting, basically with the family, the executive director of the facility, and the wellness director, and at that point, we would get together and talk about how my mother was doing. So any increase, I was aware of and was notified of the increase in services they would provide.

Senator HUTCHINSON. And you are much more satisfied now in the nursing home than the service you were able to get in the assisted living facility?

Ms. APPOLITO. I am satisfied in the service, yes. In the environment, no.

Senator HUTCHINSON. Okay. Ms. Johnson, let me just give a broad question to you. On the 134 wards that are in assisted living facilities that you are responsible for, or that you are guardian for, is there any generalized observations as far as quality of care, consumer protections that you would share with the committee on the basis of those experiences?

Ms. JOHNSON. One thing I do need to let you know, the Tampa Bay Regional Planning Council did pull all of the information they could for consumers and put together a booklet that said, this is how many assisted living facilities there are, this is how many beds they have, this is how much they charge, the range from bottom to top, and how many times they had received fines or if they had been put under a moratorium. That was a one-time grant. That happened, I do not remember how many years ago. It happened one time. It is a valuable tool. It was great.

Senator HUTCHINSON. So if there were some requirement that that kind of information be provided nationally, that would be—

Ms. JOHNSON. It would help families to sit down and be able to decide, there is an assisted living facility around the corner and it does not look like it has been hit on too many times by State regulators and so forth. That would be wonderful.

The level of care goes according to the amount of dollars. For all of my residents, those that are on State rate, which is \$22 a day, certainly do not receive the services that those persons that are paying \$100 to \$125 a day. I am not saying that the person that is on State rate has to live in a facility that is getting that much. However, there are basic needs that need to be given to all elders. They do not need to be—

Last night, I went into the assisted living facility to check Dad out to go out to dinner. The air conditioner was on. The ladies in the extended care facility had on jackets. They had on coats in Florida. I promise you, it was 85 degrees when I went in there and they had on their little jackets and they begged me, it is cold in here. Can you not fix it? No, it was Sunday evening and there is not staff that can attend to the air conditioning problem on Sunday evening. She needed heat for her family. I mean, these are things that need to be regulated and these people in the extended care facility were paying more than my father is in his villa.

So regulating, reporting abuses. We do not know that we need to report abuses. The professionals and the family members, we need to make it better. We need to tell you what is wrong so you can fix it, and I hope it gets fixed.

Senator HUTCHINSON. Thank you. Thank you, Mr. Chairman.

The CHAIRMAN. Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman. Both of you have been excellent and obviously have great expertise in the field.

Ms. Appolito, I could identify exactly with what you were talking about because on Saturday morning when I was sitting with my mother in her assisted living program, she said, "You know, Ron, my memory is not what it once was." I think your statement was very compelling.

A question for your first, Ms. Appolito. You talked about physical abuse that your mother suffered at one facility. Do you know what happened to that caregiver who physically abused your mom?

Ms. APPOLITO. The caregiver left. She left. When I brought it up to the owner of the home, because this was in a board-and-care facility, the owner had been out of town and I started my own investigation and was just questioning what happened because my mother had been aggressive with the staff when she first moved in there. It was just merely I was asking questions to determine what happened. Was it something that my mother instigated? I subsequently found that I was not getting the truth. I requested that that caregiver be terminated, but the owner would not let go of that caregiver. She left on her own, maybe three weeks later.

Senator WYDEN. Do you know if she is still giving care to seniors out there?

Ms. APPOLITO. I heard that she was, yes.

Senator WYDEN. If you could, and the Chairman, Senator Breaux, and I have all dealt with these, if you could give us that information so that we could keep it confidential but also follow it up. I mean, these are the kinds of things that we have a moral obligation to follow up on. If you have somebody who physically abused a senior citizen and they are continuing to offer care, as you suggest, that is something we have got to follow up on. If you could get that information to the Chairman and the committee, that would be helpful.

Ms. APPOLITO. Okay.

Senator WYDEN. A question I had deals with the matter of information, and the Chairman, Senator Breaux, and I have all been talking about, and frankly, I outlined some of the information problems in my opening statement. It is even worse, actually, than I outlined. In one in three situations, the residents are not even told about the circumstances under which the cost of services will change. So this information issue is exceptionally troubling.

One of the things that the three of us have talked about is, do you think it would be helpful to families to put information on the Internet so that people could learn, for example, if a facility had a host of problems? It would be our sense that because families often have to make these decisions very quickly, sometimes they are not close by, that if the committee, working with consumer groups and responsible people in the industry, could get this information on the Internet in an understandable way, that would be helpful in terms of making these choices. What would you say, Ms. Johnson?

Ms. JOHNSON. I think it would be entirely appropriate and very helpful. I have found that the families that I work with, and I work with a lot of families that are out of the State of Florida, where their parents went to retire there, the children are here working, we do more e-mail now than we do postage mail. We e-mail what is going on and what is not. Our country is checking the Internet and finding services and I think it would be great.

Ms. APPOLITO. I think it would be a great idea, as well. Any way that we could get the information out there would be beneficial.

Senator WYDEN. Mr. Chairman, the other thing that would be appealing about our looking at this issue is that it also would help

the government to target resources in areas where there were problems. We were talking earlier about how to ensure that we do not have the same problems with Medicare and Medicaid. It would seem to me if, for example, we used the Internet, we are in a position to get people information about the facilities that were problems, you would have almost the equivalent of a watch list, a kind of list that would say, look, here is a minority of facilities that you do have a problem with.

Then government regulators could zero in on those particular facilities, and as you empower the families to make better choices that are helpful for the, at the same time, government regulators could zero in on those facilities that were particularly likely to offer questionable care. So if we could pursue that, I think that would be a step forward.

The CHAIRMAN. I think after this hearing, we will have some sort of a process to follow up and that would be a legitimate part of the follow-up.

Senator WYDEN. Thank you.

The CHAIRMAN. Senator Bunning.

Senator BUNNING. Thank you, Mr. Chairman.

Let me get back to the basic reason of the hearing, which is how and what was the bottom line for you selecting the assisted living facility for your dad and for your mom. First, Ms. Johnson, what was the bottom line?

Ms. JOHNSON. The independence that it offered and the quality of care that I had, and "had" is primary, that I had been used to at that facility in the past.

Senator BUNNING. Not dollars?

Ms. JOHNSON. The dollars meant something to me, but my dad can afford to be there for some time.

Senator BUNNING. So the choice was the best facility and the convenience or closeness to you?

Ms. APPOLITO. To me, correct. My first—I chose the Arden Courts facility because it would allow my mother to remain as independent as possible. The environment was nice and they also said that they took care of Alzheimer's patients, and that was of primary concern to me. I needed a place where she was in a secure environment and they did have a secure environment.

Senator BUNNING. Did these facilities, or either area that you selected, have facilities that had personal, assisted, and skilled care in one facility?

Ms. JOHNSON. The facility in which my dad lives has the villas and they have independent living until they need supports, which he now has, which is the administration of medications, assistance to get to the dining room, and right now we are doing two-hour checks on him.

There is personal care that is available, but then there is another part of that facility which is called an extended care facility which requires a different level of licensing, which is right there on the grounds that—

Senator BUNNING. In other words, where they can get skilled care?

Ms. JOHNSON. Correct, where they can get semi-skilled. We are not talking about a nursing home.

Senator BUNNING. I am talking about a nursing home, where there is skilled care, where there is a doctor and a nurse and all the things available.

Ms. JOHNSON. Okay. So we have from independent with assistance to extended care, which is just under the level of a nursing home, and then they would have to leave that facility and go to a nursing home.

Senator BUNNING. Did you have, in the same area that you were searching for, have the same facilities where there was more than one level of care at a given facility?

Ms. APPOLITO. Yes. At the facility where she was, they did not have that continuum on the grounds, but they had a nursing home close by. This is why it is a little different, because the assisted living facility where my mother was, they had a nurse there 12 hours a day, so they could provide assistance with medications, so they could just about go up to, or so they said, that nursing level of care, unless it was an intermediate care or something like that. There were certain things that this nurse could not do, such as, I guess, IVs, medications, or something like that.

Senator BUNNING. The reason I ask that is there is a lot of overlapping care in the same facility. Some of the facilities in Kentucky have, or many of them have personal and skilled and assisted all in one and you move, as your need progresses, from one to the other. My dad just went through that before he passed away and I am very familiar with that type of care.

Ms. APPOLITO. Right.

Senator BUNNING. The problem is that once you are moved to the last round, all of the people who do not have Alzheimer's realize that they are in the final go-around. In other words, there is a realization that if you get to the skilled nursing care facility, that the next step is out the door. I think that even though the care is good, the mental attitude of the patient is not as good as it might be if it were in the personal or the other facility.

I wonder if you knew that when you were shopping for the best possible care for your parents, in other words, if you had a place to go where there were these type of facilities so you would not have to move them from one to another. Go ahead.

Ms. JOHNSON. I recognized that, because we do have that continuum of care in a lot of the facilities. We have everything from a six-bed assisted living facility to, I think, one large one has 600 beds. So, yes, we do have that continuum of care.

The hardest part of my job as a guardian is to say to them, "Hi, I am Patty. I am your guardian. I am removing you from your home." Being able to say we are not going to a nursing home, as you have just said, because that is the last thing before you die, and being able to say we are going to go to this great place where they are going to be playing bridge and someone is going to help you with these few areas that you need help with helps them, it helps everyone. Assisted living and saying, we are going to a retirement home, instead of saying, we are going to a nursing home—

Senator BUNNING. It is a big change.

Ms. JOHNSON. It is a relief. I looked at that. There is a nursing home, as she said, very close to the facility in which I placed Dad, where he lives. So although it is not on the grounds, it is close.

Senator BUNNING. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Bunning.

Senator LINCOLN.

Senator LINCOLN. Thank you, Mr. Chairman. I appreciate the leadership Senator Breaux and you have provided on this important issue.

Ms. JOHNSON, you are listed as having your father in an assisted living facility, but you also speak of a capacity in where you assist others, is that correct?

Ms. JOHNSON. Yes.

Senator LINCOLN. What is that?

Ms. JOHNSON. I am the president of a corporate guardian in Pinellas County, FL. That is St. Petersburg/Clearwater. We serve incapacitated persons in the Sixth Judicial Circuit as guardian. We serve over 200 persons in that capacity.

Senator LINCOLN. So you are the guardian that assists in placing incapacitated persons in assisted living facilities?

Ms. JOHNSON. Yes.

Senator LINCOLN. You mentioned the factors that convinced you to choose the assisted living facilities that you chose. Having gone through the experiences that you have, would you change anything? What have you learned?

Ms. APPOLITO. When I first started in this two years ago, there were not many options for someone who has Alzheimer's or a memory-related disease. Now, there are other options. I probably would have shopped a little more. I would have wanted to know the differences in the staffing levels, who is going to be there, who do you call on if something happens, if something is wrong. At the time, there just were not that many options for me.

Senator LINCOLN. Ms. Johnson and you gave reasons why you chose the facilities you did and both of you answered independence. What I would ask of you is what would be your definition of independence and how important is your definition?

Ms. JOHNSON. For my dad, it is because he has a key in his pocket and he locks the door to his villa. If he does not want to go somewhere or do something, he has the ability to say, "This is my place. Get out. No." Or he can say, "I am not going to" or "I am going to," which I would expect the staff to let me know that he refused medications, which they are supposed to under Florida rules.

But his independence is that he has his own place and he still calls his shots, for the most part. He does not make his meals. He does not do his medications. He understands so far. He does have memory loss. He is starting with dementia, and I recognize that. But at this point, it is his place and he tells them what to clean up and where and when.

Senator LINCOLN. And that was a part of the criteria you were looking for when you made your selection?

Ms. JOHNSON. Right. He did not want to share a room with someone else.

Ms. APPOLITO. For my mother, independence was very important. She was young when this started, 61, and she had always been a very independent woman. It has been very difficult for me to watch her give up the independence or have it go. I do not know that that is her choice, but she is not as independent as she was. So it was

very important that she was allowed to do whatever she could on her own.

With any type of memory-related disease, those capabilities diminish with time naturally, and they have. But as long as she could do it, I wanted her to be able to care for herself as long as she could and let the natural courses take over whenever they did.

Senator LINCOLN. You mentioned that looking in retrospect you would rather have a better knowledge of who to call on to ask questions. By instinct, who is the first person that you approached in the assisted living facilities that you chose? Was there a specific person that had a title and indicated to you that he/she was an information source? Would it be more appropriate and more helpful to the consumer to know that there is a person that you go to for information or was that confusing to you?

Ms. APPOLITO. It was not so much confusing, it is just the person you see the most is the caregiver. They are the ones that are there. So, quite naturally, I went to the first person that was there. A lot of times, I was there in the evening and that was the only person that was available. They had the pager numbers. They could get in touch with other staff. If I knew the wellness director was there and it was a care issue, I would go directly to the wellness director. But at 6:00 or 7:00, the wellness director or no other staff member was really there.

Ms. JOHNSON. I can tell you that, in Florida, the industry that we are talking about right now is, like, booming, and we get brochures in the mail every day. I am marketed daily, many times a day. Any facility of any size is sending out brochures based on—I mean, they get sweepstakes and assisted living facility brochures in the same mail, and quite often, they are invited by marketing directors, come, go to lunch with us, and they do pick them up from their home and take them to lunch. It is the marketing person that is giving out most of the information. So in Florida, in metropolitan areas—I do not know about outside—I do know that our area is doing that and it is tough.

You have to remember, in Pinellas County, we have a ton of retirees that do not have family and friends. I think that our parents are really lucky because they have us and we care and there are tons and tons of people that care about their parents and just cannot help them and feel helpless, and I feel bad for that.

Senator LINCOLN. Well, there is a lot that we are dealing with in the marketing fraud of seniors.

If I could ask one last question Ms. Appolito. Your background is in marketing, is it not?

Ms. APPOLITO. Yes, it is.

Senator LINCOLN. As a marketing professional and a consumer what are the most important questions for potential clients and family members to ask before choosing an assisted living facility?

Ms. APPOLITO. What I always encouraged potential family members and residents to do was to shop around, that they needed to feel comfortable with the facility that they chose. This was going to be their home for a period of time.

It is also important to know what the staffing ratio is so that if and when you need assistance, you are going to have it, because that is what you are paying for. In the facility where I worked, just

for basic assistance, it started at \$2,100 a month, and that is pretty steep for a lot of people. So you need to know what you are paying for and what you are going to get and that was one question that was asked of me quite frequently.

You also need to find out about deposits—that varies from facility to facility—and who you should call on, because caregivers are often overworked and underpaid and do not always follow through on the tasks that they are given.

Senator LINCOLN. Thank you, Mr. Chairman. I certainly appreciate it.

The CHAIRMAN. Thank you, Senator Lincoln.

Now, Senator Hagel.

Senator HAGEL. Mr. Chairman, thank you.

I noted that in the just released General Accounting Office survey that has been referred to here this afternoon on assisted living centers in four States, as you know, two of those four States included your two States that we are visiting about this afternoon, Ohio and Florida. According to the survey, it says the most common problems involve inadequate care, giving residents the wrong medication, and failing to give them medicines they needed, all very consistent with your testimony, each of you.

The question I have for each of you, then, if that is the case, and we heard it plainly from each of you and that has been part of the survey result from GAO, do you think these problems were as a result of mainly or mostly or some of the owners' bottom line? Has it been mismanagement? Has it been carelessness, lack of trained staff? Would you care to address that issue? Ms. Johnson, why do you not begin.

Ms. JOHNSON. Okay. I find that in the State of Florida, an assisted living facility must keep a chart of medications and when it is given out and if it was refused by the resident. All too often, if a person does not have a guardian and they refuse their medications because of their dementia, not because they did not need it but because of their dementia, they decide that afternoon they do not want their medications, an "R" is written down and that is all that happens and the person gets ill. If I become their guardian and go back and check and ask why it was not taken, it is because they refused it and it is their right to refuse it.

Lots of times, people are inadequately trained. They are, as Ms. Appolito said, trying to do too much with too little assistance and not good background, not good nursing background. It happens quite often.

In my dad's case, that morning when he was sick, that was a person in the dining room that was serving his breakfast and they never offered any assistance so he just went back and called for the only assistance he knew, which was me, and thank goodness I was home.

Ms. APPOLITO. I think a lot of it has to do with the bottom line of the company. I saw that quite a bit in my capacity as marketing director. There is a lot of pressure to build buildings and sometimes decisions are not made in the interests of the new residents. They might be made in the interest of the bottom line and the company.

This also has to do with the staff is not properly trained, I do not think. In the case of Arden Courts, where they were promoting that they take care of residents with Alzheimer's, I did not see enough evidence that they were thinking for my mother or the other residents in the facility. That is what I was paying them for. My mother cannot speak for herself. She does not talk a lot. Some residents do. Even if you ask her a question, the response could be opposite of what you would expect or what you might think the answer should be, and it was just her natural response.

It took, I think, some greater thought sometimes, that maybe they were too busy or they did not have the proper training to understand that maybe she needed more or maybe they needed to pry a little bit more to find out what really was going on. Sometimes, I had to do that, and they were supposed to be trained to do that.

Senator HAGEL. Ms. Johnson, you said we need to make it better. How do we make it better?

Ms. JOHNSON. We need to make sure that the people that ask for and receive a license in every State are monitored, that they provide the care that they say they are going to provide, that they can turn the air conditioner down at night, that they can turn the heater on during the day in the winter in Ohio, that the person that is passing out medications knows what the medications are and knows the difference between Alzheimer's and cantankerous, that those things that need to happen to make life better happen, that when my dad says, "I do not feel good," somebody says, "This is an 84-year-old man that does not feel good. Something must be wrong."

Senator HAGEL. But how do you do that? Is it a matter that the State regulators are failing?

Ms. JOHNSON. I think that the State regulators are doing what they can with what they have. I think we need to have ombudsmen. I think that we need an increase in licensure requirements and supervision and oversight. It is a new industry. I hate to overregulate anything because then it becomes overburdensome and the costs go up. However, we have got to do something because not all the seniors have children that can take care of them. Somebody has got to. We need oversight desperately.

Senator HAGEL. Thank you.

The CHAIRMAN. Thank you, Senator Hagel.

Senator Bayh.

Senator BAYH. Thank you, Mr. Chairman. I also would like to ask consent to have my opening statement submitted for the record.

[The prepared statement of Senator Bayh follows:]

PREPARED STATEMENT OF SENATOR EVAN BAYH

Thank you Mr. Chairman and Senator Breaux for holding this hearing on assisted living. As we evaluate the options our current and future seniors have for receiving medical care in a humane and timely manner, living in a secure and friendly environment, and maintaining a high quality of life, we must educate ourselves. We must educate ourselves about the fast growing industry of assisted living. That is why I am here today, to learn from those who have already taken advantage of the assisted living option, to learn about the work those in the private sector have accomplished in allowing seniors the ability to live independently while still receiving the daily assistance they may require and, I am here to learn about what actions states have taken to ensure quality of care for their citizens.

Indiana is currently learning as well. My state does not have any regulations regarding assisted living and does not provide any state funding for those in the facilities. But, with 7,000 Hoosiers in the 133 facilities Indiana is studying the industry and determining what its state level involvement should be.

It is exciting that so many seniors, over 1.2 million, have found assisted living to be the best option for them. We owe it to them to set aside some time and ask ourselves how can we improve the system. I look forward today to start the process in answering that important question.

Senator BAYH. I would like to thank our witnesses for being with us today. I apologize for being a little bit tardy, but I do appreciate your presence. I know you have busy lives of your own and it is not easy to come here and talk before all of us and share your personal stories, but it is very helpful for us that you do that.

In my own State, for example, we are one of the States that does not currently have regulations in this area. Our State also does not provide any State financial assistance to people in assisted living facilities. However, we have about 7,000 folks who do live in these facilities, I think about 113, to be almost exact, and so you are helping us learn how best to go about dealing with this important area.

I just have a couple of questions I would like to ask you. The first one, stepping back for a moment, you are here testifying before the United States Senate today, but the Federal Government to date really has not regulated or gotten involved in this area, and again with apologies for not having heard your opening statements, what was your experience with the State of Florida and the State of Ohio? Were your States doing an adequate job?

The reason I ask this is, ordinarily, we allow States to tailor-make their laws and regulations to suit the specific needs of their populations and the Federal Government only gets involved when we think that either States are not acting or they are acting and not doing a very good job of it. Could you just share with me briefly your opinion about how Florida and Ohio are doing? We are having another panel after you, so some ears may perk up a little bit listening for your response.

Ms. APPOLITO. I think Ohio is doing an okay job. I think that this industry has grown so fast that this is why we are here today. In Westlake alone, in the beginning of 1997, there were no choices for someone with Alzheimer's disease in an assisted living capacity and now there are four. In one little suburb of Cleveland, OH, there are now four offering high-end services for people that need assistance and also assistance with Alzheimer's. It is interesting to me how quickly this industry has grown.

I think, though, that at this point, it is a good time to start looking at it because there are inadequacies that are happening in the facilities themselves and we need to do something to make sure that—in my case, I moved my mother from San Diego to Ohio and it was very difficult to do that. If I could have left her in San Diego, where she spent over 30 years, that probably would have been my first choice, if that were an option. But crossing State lines, there is such a vast difference in the services that are provided in the facilities themselves that I think there is probably some regulation or something that we can do to help family members out, especially in a time of crisis.

Senator BAYH. So some uniformity in this case might have been helpful for you, since in California you might have been somewhat familiar with one set of regulations or standards but you moved your mom to Ohio and you had to relearn it all over again?

Ms. APPOLITO. It was completely different. It was completely different.

Senator BAYH. You mentioned the importance of being an informed consumer and having people look around. To the extent we live in a mobile society and folks are having to relocate their parents, I guess that makes it a little more difficult to be the informed consumer you talked about, if the regulations and standards vary substantially from State to State. Would that be a fair observation?

Ms. APPOLITO. Yes.

Senator BAYH. So your answer is Ohio is doing okay. Is that "okay" pretty good, or just okay?

Ms. APPOLITO. I think just okay. I think there is always room for improvement.

Senator BAYH. It sounds like they are trying to keep up with a fast evolving and growing industry, so that is always more difficult in a situation. Thank you.

How about Florida?

Ms. JOHNSON. I think Florida has a real extensive background in assisted living facilities. They have had a lot of them for a lot of years. However, from what I can find out, last year, Florida was adding 85 assisted living facilities per month. So it is an explosive, huge, multi-million dollar industry. When things are happening that fast with that many dollars, there are problems that occur.

I think that our State is doing a good job, but I can tell you that on Medicaid waivers, what our State has, the State rate is \$22 a day. There is a Medicaid waiver program that will bring it from approximately \$650 a month for a person with no funds to \$1,200 a month in an assisted living facility. There is an eight- to ten-month wait for those funds. So the person that would receive that Medicaid waiver and live in a better facility is going to live in the \$650 a month facility, and I can tell you I would not let my dad live in one of those facilities. I would not.

Senator BAYH. In the \$650 a month?

Ms. JOHNSON. I would not let him live in a \$650 a month facility. He would be at home with me. There is no way.

Senator BAYH. Mr. Chairman, my time has run out. May I have permission to ask one more question?

The CHAIRMAN. Yes.

Senator BAYH. You have the \$650 facility, then you mentioned a \$1,200 a month facility, which I gather in your opinion would be substantially better. Ms. Appolito mentioned the price for you started at \$2,100 a month?

Ms. APPOLITO. Right.

Senator BAYH. What is the difference between them? I mean, you go from \$650 to \$1,200 to \$2,100. Twenty-one-hundred is a lot of money. What is the difference in the quality of care you get among these three types of facilities?

Ms. JOHNSON. My dad started out at \$1,500 a month, was paying \$1,700 a month just recently, and will be paying more at the end of the month because of his increased needs. But the same facility

that he is living at accepts Medicaid waiver, but they are only allotted a few slots of that Medicaid waiver money. We need tons of Medicaid waiver money. They could be living—

Senator BAYH. Is it the State, or you may not know—

Ms. JOHNSON. The Medicaid waiver program has Federal assistance along with State assistance, and it is given to the, I believe it is Title II—is Title II the Older Americans Act—whoever distributes that money in our district is the one that decides who gets those Medicaid waiver slots.

Senator BAYH. They allocate the slots?

Ms. JOHNSON. They allocate the slots.

Senator BAYH. Thank you both. Again, Mr. Chairman, I would just like to conclude by saying it is my understanding you both touched upon Alzheimer's, and this is going to be a growing public policy challenge for our country. As more and more Americans suffer from this infliction, it is important that we get it right, so I appreciate again your helping us to do that.

The CHAIRMAN. Thank you, Senator Bayh.

Before I say goodbye to you and thank you, could you answer yes or no to one question. In either one of your cases, did your family members have long-term care insurance?

Ms. APPOLITO. No.

Ms. JOHNSON. No.

The CHAIRMAN. Thank you very much.

I join all of my colleagues who have complimented you for contributing to this debate for the Congress to begin opening access to information about a subject that Congress has not paid much attention to in the past. We thank you very much for giving us your firsthand experience. We realize the trauma that you have gone through can be an example for all of us as we try to educate consumers about assisted living. Thank you very much. You are welcome to stay if you want to stay and hear the other witnesses.

The CHAIRMAN. I am pleased to introduce our first witness on the second panel, Ms. Kathryn Allen. She is Associate Director of the General Accounting Office's Health Financing and Public Health Issues. The General Accounting Office has become a fixture at the Aging Committee hearings and events. As always, we appreciate the work of the General Accounting Office and are glad to have Ms. Allen here representing that agency.

Next, we hear from Dr. Catherine Hawes. She is senior research scientist at the Myers Research Institute of Menorah Park Center for the Aging, Cleveland, OH. She is testifying today in her capacity as principal and project director for the assisted living study conducted by the Department of Health and Human Services.

Next, we will hear from Dr. Robert Mollica. He is going to present testimony on his research in the field of long-term care and assisted living. He is deputy director of the National Academy for State Health Policy, a nonprofit organization from Portland, ME.

Our final witness for our second panel will be Cindy Hannum. She is assistant administrator to the Oregon Department of Human Resources, Senior and Disabled Services Division. Ms. Hannum has extensive experience in the quality of care and consumer issues in the long-term care setting.

I wonder if you would like to say anything about Ms. Hannum.

Senator WYDEN. Thank you, Mr. Chairman. I will only say that I have known her and her department, really, since my days with the Gray Panthers and we are so glad that she is here. Oregon has sought to be a model in the long-term care area and we welcome you and look forward actually to hearing from you and all our colleagues. Thank you, Mr. Chairman.

The CHAIRMAN. My staff has advised me I did not say Mollica right.

Mr. Mollica. Actually, that is the correct pronunciation, but we changed it to Mollica.

The CHAIRMAN. I guess I just know everything.

We are going to start with Ms. Allen. Because of the period of time that we have left, we would hope that you can summarize your statements in the five minutes that have been allotted so that we can have time for questioning and still hear our final panel and give them the appropriate time that they deserve. Remember that your entire statement will be printed in the record as you write it, and I hope that is your desire.

Ms. Allen.

**STATEMENT OF KATHRYN G. ALLEN, ASSOCIATE DIRECTOR,
HEALTH FINANCING AND PUBLIC HEALTH ISSUES, HEALTH,
EDUCATION, AND HUMAN SERVICES DIVISION, GENERAL AC-
COUNTING OFFICE**

Ms. ALLEN. Thank you, Mr. Chairman and members of the committee. I am pleased to be here today to discuss the GAO report, alluded to already today, that we have issued to you on quality of care and consumer protection issues in assisted living facilities in four States, which include California, Florida, Ohio, and Oregon.

Assisted living offers a combination of housing, meals, personalized support services, and in some cases health care for their residents. Currently, the assisted living industry is predominately funded by private resources and is licensed and regulated by the States. Our report provides detailed information on the wide variation in the types of services these facilities provide, the differing needs of the residents they serve, and the approaches the four States use to oversee these services.

In the interest of time, I will focus my remarks today on two issues, the extent to which facilities provide consumers with information that helps them choose the facility that best meets their needs, and the types of quality of care and consumer protection problems that States have already identified.

Given the variation in what is labeled assisted living, prospective residents must tap into a variety of resources for information. In addition to facility tours, personal interviews, and recommendations, they must be able to rely on written information, such as marketing material and sample resident agreements or contracts that are directly available from facilities they are considering.

As you can see from the first chart on your right, the majority of facilities that we surveyed reported that they do provide written information to prospective residents on basic services and their cost, on residents' rights and responsibilities, and on complaint or grievance procedures. However, about only half indicated that they provide written information on their policy for medication assist-

ance, their practice for monitoring residents' needs, or the circumstances under which the cost of services may change. And even fewer, about one in three, indicated that they provide written information on things such as staff training and qualifications.

By reviewing a sample of the written materials that facilities do provide to prospective residents, we found that about one-third contained information that was often vague, confusing, or misleading. This most often concerned the circumstances under which a facility may require a resident to leave. Our second chart illustrates this.

The marketing material for one facility, for example, says, "If health changes occur, we can meet your needs and you will not have to deal with the hassles of moving again." But the facility's contract specifies a range of health-related criteria for immediate discharge, including changes in a resident's condition or need for services that the facility cannot provide. In this case, the contract is clearly inconsistent with the promise of the marketing material for what is known as "aging in place."

Now, I will turn to the second issue, which is quality of care and consumer protection problems that States identified. Using available State inspection surveys and other oversight reports, such as that available from ombudsmen, we found that the States had cited over one-fourth of the facilities in our sample for five or more quality of care or consumer protection problems. Most of these related to quality of care issues, such as inadequate care, staffing, or medication issues.

Our third chart illustrates the nature and range of problems the States identified. This includes examples of inadequate care that led to a resident's death, insufficient staff to provide such basic care as changing residents' soiled garments, and serious medication administration issues, including staff inaccurately transcribing physicians' medication orders.

The chart also portrays consumer protection problems that States identified. For example, one resident, after living in a facility for two years and being told on admission that she could stay until she died, began to wander within the facility, although not beyond its confines. The facility quadrupled her monthly fee and gave her a two-week eviction notice.

In conclusion, Mr. Chairman, our work indicates that as a growing number of elderly Americans reach the point where they can no longer live independently, many are looking to assisted living as a viable home-like setting to meet their needs. While many residents enter these facilities with relatively few or minimal needs for supportive or health services, their needs often do increase with age or with declining health, as we have already heard. Some assisted living facilities may be able to accommodate these changing and more intensive needs; others may not. Fully understanding the strengths and limitations of facilities and having confidence in the quality assurance and oversight mechanisms are all important as consumers and their families attempt to make the best choice for what is often a very difficult decision.

Mr. Chairman, this concludes my comments.

[The prepared statement of Ms. Allen follows.]

United States General Accounting Office

GAO

Testimony

Before the Special Committee on Aging,
U.S. Senate

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ASSISTED LIVING

Quality-of-Care and
Consumer Protection
Issues

Statement of Kathryn G. Allen, Associate Director,
Health Financing and Public Health Issues
Health, Education, and Human Services Division



GAO/T-HEHS-99-111

Mr. Chairman and Members of the Committee:

We are pleased to be here today to discuss quality-of-care and consumer protection issues in assisted living. Assisted living facilities are becoming an increasingly popular option for providing long-term care for the elderly in what can be a less costly and more homelike setting than nursing homes. Current estimates of the number of assisted living beds in the United States range from 800,000 to 1.5 million, and consumer demand is expected to grow significantly as the projected number of elderly Americans in need of long-term care doubles over the next 20 years.

Assisted living facilities offer a combination of housing, meals, personal support services, and, in some cases, health care for their residents. Although most assisted living is paid for privately by individuals and their families, many states are using Medicaid to fund services and care for residents in assisted living facilities, and others are considering whether assisted living can be a cost-effective alternative to publicly funded nursing home care for some persons. At the same time as interest in assisted living has grown, concerns about quality of care and consumer protection in assisted living have been raised in recent media accounts and other reports.

The information I am presenting is based on a report we are issuing to your Committee today that examined assisted living in four states—California, Florida, Ohio, and Oregon.¹ My statement focuses on four main issues:

- residents' needs and the services provided in assisted living facilities;
- the extent to which facilities provide consumers with sufficient information for them to choose a facility that is appropriate for their needs;
- the four states' approaches to oversight of assisted living; and
- the types of quality-of-care and consumer protection problems they identify.

Our findings are based on an analysis of responses to a mail survey of facilities in these four states, an evaluation of the facilities' marketing materials and contracts, interviews with state officials, a review of relevant state statutes and regulations, visits to 20 assisted living facilities, interviews with more than 90 assisted living residents or

¹Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States (GAO/HEHS-99-27, Apr. 26, 1999).

family members, and an analysis of state data on verified quality-of-care and consumer protection problems in assisted living facilities.²

In brief, we found that assisted living facilities vary widely in the types of services they provide and the residents they serve. They range from small, freestanding, independently owned homes with a few residents to large, corporately owned communities that offer both assisted living and other levels of care to several hundred residents. Some assisted living facilities offer only meals, housekeeping, and limited personal assistance, while others provide or arrange for a range of specialized health and related services. They also vary in the extent to which they admit residents with certain needs and whether they retain residents as their needs change.

Given the variation in what is labeled assisted living, prospective residents must rely on information supplied to them by facilities to select one that best meets their needs and preferences. However, we found that, in many cases, assisted living facilities did not routinely give consumers sufficient information to determine whether a particular facility could meet their needs, for how long, and under what circumstances. For example, many facilities did not provide prospective residents with written information on such key issues as the amount of assistance they could expect to receive with medications, the circumstances under which the cost of services might change, or when they could be required to leave if their health changes. Moreover, we identified numerous examples of vague, misleading, or even contradictory information contained in written materials that facilities provide to consumers.

The states have the primary responsibility for the oversight of care furnished to assisted living facility residents. All four states we reviewed have licensing requirements that must be met by most facilities providing assisted living services, and state licensing agencies routinely inspect or survey facilities to ensure compliance with state regulations. However, the licensing standards as well as the frequency and content of the periodic inspections vary across the states. The licensing agencies also respond to complaints they receive related to potential violations of state regulations. In addition, the long-term care ombudsman agency in all four states and the Adult Protective Services (APS) agency in Florida and Oregon investigate complaints or allegations of problems involving residents of assisted living facilities.

²We sent our mail survey to 955 randomly selected facilities of 2,652 identified potential providers of assisted living in the four states. We received responses from 721 facilities, or 75 percent of those we surveyed, 622 of which identified themselves as providers of assisted living services. Our analysis of quality-of-care and consumer protection issues was based on a review of state licensing agency deficiencies, ombudsman complaints, and adult protective service allegations that state officials verified in a sample of 753 facilities in these states.

Given the absence of any uniform standards for assisted facilities across the states and the variation in their oversight approaches, the results of state licensing and monitoring activities on quality-of-care and consumer protection issues also vary, including the frequency of identified problems. However, using available inspection surveys and reports from the other oversight agencies in the four states, we determined that the states cited more than 25 percent of the 753 facilities in our sample for five or more quality-of-care or consumer protection related deficiencies or violations during 1996 and 1997. Eleven percent of these facilities were cited for 10 or more problems during this time period. Most of the problems identified by the state agencies were related to quality-of-care rather than consumer protection issues. While data were not available to assess the seriousness of each identified problem, many problems seemed serious enough to warrant concern. Frequently identified problems included facilities providing inadequate or insufficient care to residents; their having insufficient, unqualified, and untrained staff; and their not providing residents appropriate medications or storing medications improperly. State officials attributed most of the common problems identified in assisted living facilities to insufficient staffing and inadequate training, exacerbated by high staff turnover and low pay for caregiver staff.

BACKGROUND

Assisted living is usually viewed as a residential care setting for persons who can no longer live independently and who require some supervision or help with activities of daily living (ADL) but may not need the level of skilled care provided in a nursing home. It is promoted by assisted living advocates as a long-term care setting that emphasizes residents' autonomy, independence, and individual preferences and that can meet their scheduled and unscheduled needs for assistance. Typically, assisted living facilities provide housing, meals, supervision, and assistance with some ADLs and other needs such as medication administration. However, there is no uniform assisted living model, and considerable variation exists in the types of facilities or settings that hold themselves out to be an assisted living facility. In some cases, assisted living facilities may serve residents who meet the level-of-care criteria for admission to a nursing home.

Unlike residents of nursing homes, the majority of whom receive some support from Medicaid or Medicare, most residents of assisted living facilities pay for care out of pocket or through other private funding.³ However, public sources of funding are

³Medicaid is the federal-state health financing program for low-income and aged, blind, and disabled people. Medicare finances health care for most Americans over age 65 and the disabled. In 1999, the federal government is projected to pay \$39 billion for nursing home care, mostly through Medicaid.

available to help pay for services for some residents. For example, some states are attempting to control rising Medicaid costs by encouraging the use of assisted living as an alternative to more expensive nursing home care. Currently, 32 states use Medicaid funds to reimburse for services provided to Medicaid beneficiaries residing in assisted living facilities.⁴ However, Medicaid payments do not cover the cost of room and board in assisted living facilities. A combination of individuals' personal resources, residents' Supplemental Security Income (SSI) payments, and optional state payments pay for these costs.

The states have the primary responsibility for overseeing the care that assisted living facilities provide residents, and few federal standards or guidelines govern assisted living.⁵ The four states we reviewed vary widely in what they require of these facilities. Generally, state regulations focus on three main areas—requirements for the living unit, admission and retention criteria, and the types and levels of services that may be provided. Some states have set very general criteria for the type of resident who can be served and the maximum level of care that can be provided, while other states have set more specific limits in these areas, such as not serving residents who require 24-hour skilled nursing care.

ASSISTED LIVING FACILITY SERVICES AND RESIDENT NEEDS VARY WIDELY

A wide variety of services are available to residents in assisted living, and most facilities provide oversight to monitor and supervise their residents. These oversight responsibilities generally include providing 24-hour supervision; monitoring changes in residents' health and functioning; notifying a resident's physician, family, or other responsible person when the resident's condition changes; and providing regular health or wellness checks. Assisted living facilities in our survey reported that they usually provide housekeeping, laundry, meals, transportation to medical appointments, special diets, and assistance with medications. Many facilities also provide skilled nursing services, skilled therapy services, and hospice care for their residents. More specialized services, such as intravenous (IV) therapy and tube feeding, are least likely to be available. Some services may be provided by facility staff or by staff under

⁴See *State Assisted Living Policy: 1998* (Portland, Me.: National Academy for State Health Policy, June 1998). States often use the authority available under section 1915 (c) of the Social Security Act, which enables them to fund nursing services in a home and community-based setting rather than in an institutional setting.

⁵For further information on federal programs' responsibility related to assisted living, see *Long-Term Care: Consumer Protection and Quality-of-Care Issues in Assisted Living* (GAO/HEHS-97-93, May 15, 1997).

contract to the facility. In other cases, the facility may arrange with an outside provider to deliver some services, with residents paying the provider directly, or residents may arrange and pay for services on their own.

We found considerable variation among facilities and among states in the needs of the residents they serve. The facilities we visited have some residents who are completely independent and ambulatory, some who have severe cognitive impairments, and some who are bedridden and require significant amounts of skilled nursing care. Residents of assisted living facilities typically need the most assistance from facility staff with medications and bathing. Assistance with dressing and toileting or incontinence care are the next most frequently cited needs, and assistance is needed to a lesser extent with eating, transferring, and walking. The highest level of resident need for staff assistance with ADLs was reported among facilities in Oregon and those in Florida licensed as extended congregate care facilities. In addition, residents often have some degree of cognitive impairment, such as significant short-term memory problems, disorientation much of the time, or Alzheimer's disease or another form of dementia.

The ability of residents to remain in a facility as their health declines or their needs change, commonly referred to as aging in place, is determined largely by admission and discharge criteria. There is considerable variation across the states in these criteria, some of which comes from state regulations, some the facilities' choice of whom to serve, and some the particular services a facility chooses to provide or make available. For example, facilities in Oregon are more likely to admit and retain residents with a higher level of need than those in other states. Facilities responding to our survey vary in terms of resident needs they accept on admission and the circumstances under which they retain or discharge residents who develop certain needs or conditions after being admitted. Although some facilities may not admit residents with a particular need or condition, they do not necessarily discharge them if they develop that need. For example:

- More than 75 percent of the facilities reported that they admit residents who have mild to moderate memory or judgment problems, are incontinent but can manage on their own or with some assistance, have a short-term need for nursing care, or need oxygen supplementation.
- Less than 10 percent of the facilities admit residents who are bedridden, require ongoing tube feeding, need a ventilator to assist with breathing, or require IV therapy, and most facilities discharge residents who develop these needs.
- Most facilities in Oregon indicated that they do not admit people who are bedridden, but half typically retain anyone who becomes bedridden while a resident.

**CONSUMERS MAY LACK ADEQUATE INFORMATION TO
SELECT A FACILITY THAT BEST MEETS THEIR NEEDS**

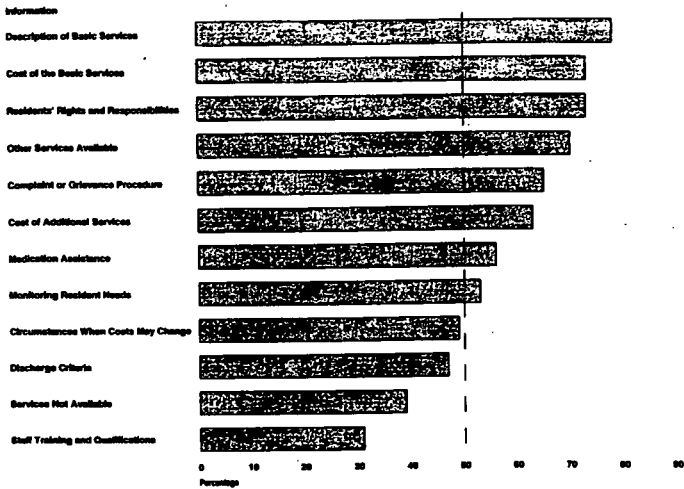
Given the variation in what is labeled assisted living, prospective residents must rely primarily on information supplied to them by facilities to select one that best meets their needs and preferences. They can obtain information in a variety of ways, including written materials, facility tours, personal interviews, and personal recommendations. However, in order to help prospective residents compare facilities and select the most appropriate setting for their needs, key information should be provided in writing and in advance of their decision to apply for admission. Yet we found that written material often does not contain key information; facilities do not routinely provide prospective residents with important documents, such as a copy of the contract, to use as an aid in decisionmaking; and written materials that are available are sometimes confusing or even misleading.

According to consumer advocates and provider associations, consumers need to be informed about the services that will be provided, their costs, and the respective obligations of both the resident and the provider. Such information should include

- the cost of the basic service package and what it includes;
- the availability of additional services, who will provide them, and their cost;
- the circumstances under which costs may change;
- how the facility monitors resident health care;
- the qualifications of staff who provide personal care, medications, and health services;
- discharge criteria, such as when a resident may be required to leave the facility, and the procedures for notifying and relocating the resident; and
- grievance procedures.

The majority of facilities responding to our survey said they generally provide prospective residents with written information about many of their services and costs in advance of their choosing to apply for admission. However, as shown in figure 1, only about half indicated that they provide information on the circumstances under which the cost of services may change, their policy on medication assistance, or their practice for monitoring residents' needs, and less than half indicated that they provide written information in advance about discharge criteria, staff training and qualifications, or services not covered or available from the facility.

Figure 1: Percentage of Facilities Reporting That They Provide Key Written Information to Prospective Residents

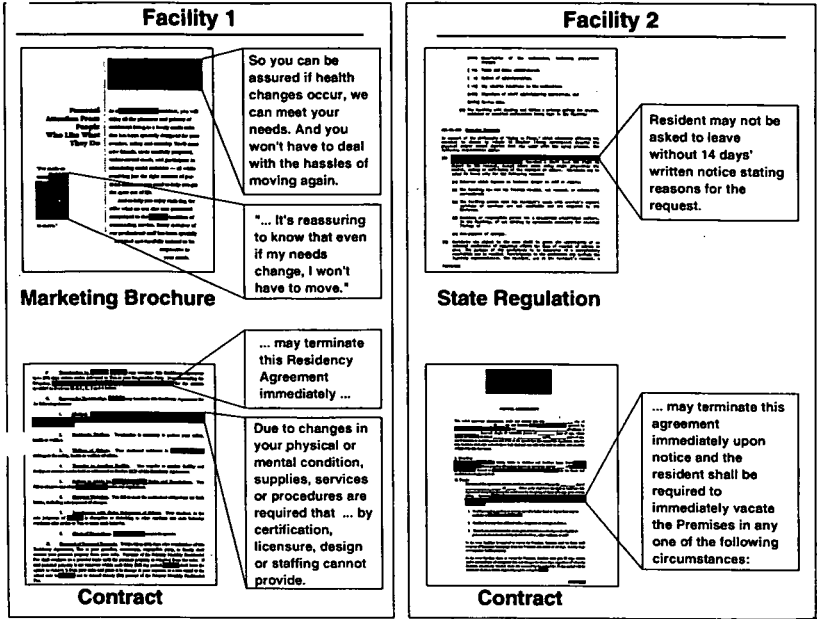


The contract or resident agreement is an important source of written information, and in some cases it may be the only place where certain key points such as discharge criteria or circumstances when costs may change are addressed. However, only one out of four facilities we surveyed indicated that they routinely provide a copy of the contract to consumers before they make a decision to apply for admission. About 65 percent of the facilities said they provide a copy when one is requested, and 10 percent said they do not generally provide contracts to prospective residents. Contracts range from a one-page standard form lease to a 55-page document with attachments. Some are written in very fine print, while others are prepared in large, easy-to-read type. Some contracts are complex documents written in specialized legal language, while others are not. Marketing and other written material provided by the facilities also vary widely from a one-page list of basic services and monthly rent to multiple documents of more than 100 pages.

We examined written marketing materials and contracts from 60 of the facilities that responded to our survey to determine whether they were complete, clear, and consistent with state laws. While most of the facility materials we reviewed were specific and relatively clear, we found that materials from 20 of the 60 facilities contained language that was unclear or potentially misleading, usually concerning the circumstances under which a resident could be required to leave a facility. Contracts and other written materials we reviewed were often unclear or inconsistent with each other or with requirements of state regulation regarding how long residents could remain as their needs change, resident notification requirements, and other procedural requirements for discharge. For example, the contract from a California facility was vague regarding the circumstances under which a resident could be required to move. It stated that the facility can discharge a resident for good and sufficient cause without elaborating on what the cause might be. The contract also failed to refer to state regulations that provide specific criteria for discharge or eviction.

As shown in figure 2, the marketing material one Florida facility uses is potentially misleading in specifying that residents can be assured that if their health changes, the facility can meet their needs and they will not have to move again. However, the facility's contract specifies a range of health-related criteria for immediate discharge, including changes in a resident's condition or need for services that the facility cannot provide. The contract of an Oregon facility is inconsistent with requirements of state regulation regarding notification of residents before discharging them. Oregon regulations specify that residents may not be asked to leave without 14 days' written notice that a facility cannot provide the services they need. However, the facility's contract specifies that residents can be required to move immediately if they need more care than is available at the facility.

Figure 2: Examples of Unclear or Misleading Written Information



THE STATES USE A RANGE OF APPROACHES TO OVERSEE ASSISTED LIVING FACILITIES

Each of the four states we studied has licensing requirements that must be met by most facilities that provide assisted living services. Florida and Oregon have created a specific licensing category and requirements for assisted living facilities, while California and Ohio license these facilities under existing residential care facility regulations. All four states have similar requirements regarding the type and level of services that assisted living facilities must provide residents. In addition to basic accommodations such as room, board, and housekeeping, all the states require

facilities to provide residents with basic services, including assistance with ADLs, ongoing health monitoring, and either the provision of or arrangement for medical services, including transportation to and from those services as needed.

All four states require assisted living facilities to conduct an initial assessment of a resident's health, functional ability, and needs for assistance. They also require that facilities provide residents with reasonable advance notice of discharge or eviction, and they specify certain rights and procedures for residents to appeal or contest a facility's decision to discharge them. State regulations also generally contain other consumer protection provisions such as those governing resident contracts, criminal background checks for staff, and residents' rights. All four states require that facilities enter into contracts with residents, but they differ in the level of detail they require in these agreements. In addition, all four states require criminal background checks for direct care staff, and three states—California, Florida, and Oregon—require them for facility administrators as well.

State regulations often differ, however, with respect to the level of skilled nursing or medical care that facilities can provide to residents and in the circumstances under which it can be provided. For example, California regulations contain a list of services that facility staff are generally not allowed to provide, such as catheter care, colostomy care, and injections. In contrast, Oregon has no explicit restrictions on the care that facility staff may provide, except that certain nursing tasks must be either assigned or delegated to a caregiver by a registered nurse. In addition, while all four states require facilities to provide some degree of supervision with medications, they differ in the degree to which facility staff can be directly involved in administering medications to residents. For example, in California, facility staff may not administer medications but may only assist residents to take their own medications. Requirements for staff levels, qualifications, and training also vary among the states. For example, Florida requires facilities to maintain a minimum number of full-time staff that is based on the total number of residents, California and Ohio require only that the number of staff be adequate to meet the needs of residents, and Oregon does not have any minimum staffing requirement.

To ensure that assisted living facilities comply with the various licensing requirements, all four states conduct periodic inspections or surveys of facilities, and they may also conduct more frequent inspections in response to specific complaints.⁶ However, the

⁶In Florida, Ohio, and Oregon, the agency with responsibility for inspecting assisted living facilities also has responsibility for nursing homes. In contrast, responsibility for the regulation and inspection of assisted living facilities in California rests with the Department of Social Services, while nursing homes fall under the jurisdiction of the Department of Health Services.

four states vary in the frequency and content of assisted living facility inspections. The frequency of required licensing inspections ranges from at least twice a year for extended congregate care facilities in Florida to at least once every 2 years for assisted living facilities in Oregon.⁷ The content of periodic state surveys is driven primarily by the requirements in state regulations. To assist surveyors, Florida and Ohio have developed detailed guidelines, similar to those used for nursing home inspections. In contrast, surveyors in California and Oregon use a checklist that covers a subset of the regulations and focuses on a few selected elements.

In addition to the state licensing agency, other state agencies play a role in the oversight of assisted living facilities. In the four states we examined, the state ombudsman agency has a role in overseeing the quality of care and consumer protection of residents in assisted living. The ombudsmen are intended to serve as advocates to protect the health, safety, welfare, and rights of elderly residents of long-term care facilities and to promote their quality of life. One of their primary responsibilities is to investigate and resolve complaints of residents in long-term care facilities, such as nursing homes, board and care homes, and assisted living facilities. Ombudsmen in Florida are also required to inspect each facility annually to evaluate the residents' quality of care and quality of life. In two of the four states, Florida and Oregon, APS agencies are responsible for investigating reports of alleged abuse, neglect, or exploitation of assisted living residents; determining their immediate risk and providing necessary emergency services; evaluating the need for and referrals for ongoing protective services; and providing ongoing protective supervision.

**THE STATES IDENTIFY QUALITY-OF-CARE AND
CONSUMER PROTECTION PROBLEMS
IN ASSISTED LIVING FACILITIES**

Given that the states vary in their licensing requirements for assisted living facilities and in their approaches to oversight, the type and frequency of quality-of-care and consumer protection problems identified by the states may not fully portray the care and services the facilities actually provide. Facilities in states with more licensing standards, more frequent inspections, or more agencies involved in oversight may be more likely to have more problems identified and verified. Using available data and reports from state licensing, ombudsman, and APS agencies in the four states, we determined that 27 percent of the 753 facilities in our sample were cited for five or more quality-of-care or consumer protection related problems during 1996 and 1997. Most of these verified problems pertained to quality-of-care rather than consumer protection issues. As table 1 shows, 22 percent of the facilities we sampled had 5 or

⁷Florida has multiple categories of assisted living licensure, including standard assisted living, limited nursing services, and extended congregate care.

more verified quality of care problems during the period, and 9 percent of the facilities had 10 or more.

Table 1. Percentage of Facilities With Quality-of-Care and Consumer Protection Related Problems Identified by Licensing, Ombudsman, and APS Agencies in the Four States

Number of problems	Facilities with verified problems		
	Quality of care or consumer protection	Quality of care	Consumer protection
5 or more	27%	22%	3%
10 or more	11	9	0

Note: Number of facilities=753.

The most commonly cited quality of care problems included inadequate care, staffing, and medication issues. These problems included instances in which a facility was found to be providing inadequate care to residents as well as instances in which a facility did not demonstrate the capacity to provide sufficient care. For example, staffing problems included cases in which residents suffered harm as a result of insufficient numbers of staff in the facility, as well as cases in which facilities had no documentation to substantiate that required caregiver training had been provided.

Inadequate care, such as instances of residents not receiving appropriate access to physicians and other needed medical care or treatment, was the most frequently cited quality-of-care problem. For example, as illustrated in table 2, in one California facility, staff neglected to call "911" after a resident fell and injured her head. Instead, they gave her aspirin, and several hours later she was found in a comatose state. She died 3 days later. The second most frequently cited problem concerned staff qualifications and training and facilities not having sufficient staff to care for the residents. For example, in an Oregon facility, family members routinely assisted residents by changing soiled garments because the facility did not have enough staff.

Table 2: Examples of Quality-of-Care and Consumer Protection Problems

Issue	Problem
Quality of care	
Inadequate care	Staff neglected to call "911" after a resident fell and injured her head. Instead, they gave her aspirin, and several hours later she was found in a comatose state. She died 3 days later.
Staffing	Because of insufficient staff, family members in one facility routinely assisted residents by changing soiled garments.
Medication	Facility staff inconsistently and inaccurately transcribed physicians' medication orders, often allowed sharing of medications between residents, signed out narcotics on one shift but had staff from another shift administer them, and allowed unlicensed caregivers to alter residents' prescription labels.
Consumer protection	
Billing or discharge	A resident was told on admission that she could stay in the facility until she died. After living at the facility for 2 years, she began to wander within the facility. The facility then issued a 2-week eviction notice stating that it could no longer care for her. The facility also increased her monthly fee from approximately \$1,600 to more than \$6,400. She moved to another facility.
Contracts	A resident contract did not contain all state-required elements, such as the basic daily, weekly, or monthly rate and a list of available services and fees not included in the basic rate.

The third most frequently cited problem concerned medication-related issues, such as not providing residents their prescribed medication, providing them the wrong medication, or storing medication improperly. For example, an Oregon facility was found to have numerous medication problems, including (1) staff inconsistently and inaccurately transcribing physicians' medication orders to the residents' medication administration records, (2) medications often being borrowed or shared between residents, (3) one staff member signing out narcotics but another staff member on a different shift administering them to residents, and (4) unlicensed caregivers altering residents' prescription labels.

Commonly cited consumer protection problems included those related to circumstances under which a resident could be required to leave a facility for health or financial reasons and those related to provisions in resident contracts. For example, a resident of an Oregon facility was told on admission that she could stay

until she died. However, the facility issued her an eviction notice when she began to wander within the facility, and it raised her monthly charge from approximately \$1,600 to more than \$6,400. In Florida, a facility was cited for not having all state-required elements in the resident contract, such as the basic daily, weekly, or monthly rates and a list of available services and fees not included in the basic rate.

In Florida and Oregon, the two states in which APS agencies have some responsibility for oversight of residents in assisted living facilities, resident abuse was also often cited. In Oregon, the APS agency verified 48 cases of abuse in 21 of the state's 83 assisted living facilities during 1996 and 1997. In one case, a resident was left on the toilet for 2 hours because the caregiver forgot to return to the resident's room, and there was no call button within reach. In Florida, the APS agency verified 39 cases of abuse in 25 facilities and 103 cases of neglect in 32 facilities during the 2-year period. Florida cases included an instance in which a 90-year-old resident was admitted to a hospital with a stage IV pressure ulcer and found to be dehydrated and poorly nourished.

CONCLUSIONS

As a growing number of elderly Americans reach the point where they can no longer live independently, many look to assisted living facilities as a viable, homelike setting to meet their long-term care needs. While many residents may enter assisted living facilities with relatively few or minimal needs for supportive or health services, these needs generally increase with age or with declining health. Some assisted living facilities may be able to accommodate these changing and more intensive needs, while others may not. Fully understanding the strengths and limitations of facilities is important as consumers and their families attempt to make the best choice for what is often a difficult decision.

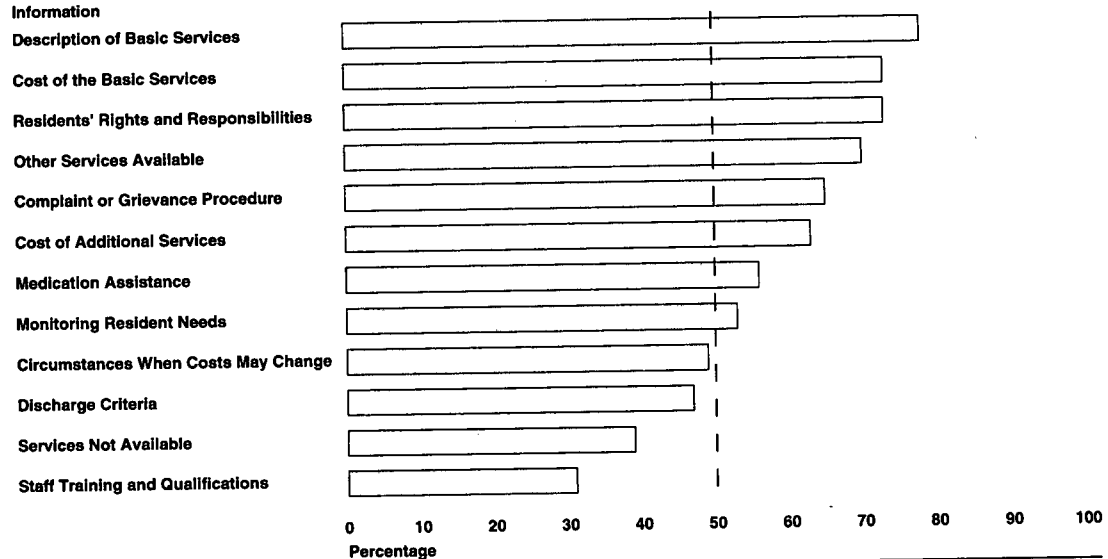
Currently, the assisted living industry is predominantly funded by private resources and is licensed and regulated by the states. However, as the states increase their use of Medicaid to help pay for assisted living, the contribution of federal financing will grow as well. This trend will no doubt focus more attention from consumers, providers, and the public sector on several issues, including where assisted living fits on the continuum of long-term care, on standards needed to ensure quality of care and protect consumers, on appropriate approaches to ensure compliance with those standards, and on the adequacy of information available to help inform consumers' choices and decisions.

Mr. Chairman, this concludes my statement. I will be happy to answer any questions that you or other members of the Committee may have.

(101815)

Alt/Key
chart 1

GAO Assisted Living Facilities Providing Key Written Information to Prospective Residents



GAO Examples of Unclear or Potentially Misleading Written Material

Facility 1

Marketing Brochure

Personal Assistance Programs Available When Life What They Do

So you can be assured if health changes occur, we can meet your needs. And you won't have to deal with the hassles of moving again.

... It's reassuring to know that even if my needs change, I won't have to move."

Contract

... may terminate this Residency Agreement immediately ...

Due to changes in your physical or mental condition, supplies, services or procedures are required that ... by certification, licensure, design or staffing cannot provide.

Facility 2

State Regulation

Resident may not be asked to leave without 14 days' written notice stating reasons for the request.

Contract

... may terminate this agreement immediately upon notice and the resident shall be required to immediately vacate the Premises in any one of the following circumstances:

GAO Examples of Quality of Care and Consumer Protection Problems in Assisted Living Facilities

Quality of Care

Inadequate Care Staff neglected to call "911" after a resident fell and injured her head. Instead, they gave the resident aspirin, and several hours later the resident was found in a comatose state. The resident died 3 days later.

Staffing Because of insufficient staff, family members in one facility routinely assisted residents by changing soiled garments.

Medication In one facility, staff inconsistently and inaccurately transcribed physician medication orders, often allowed sharing of medications between residents, signed out narcotics on one shift but had staff from another shift administer them, and allowed unlicensed caregivers to alter residents' prescription labels.

Consumer Protection

Billing/Discharge A resident was told on admission that she could stay until she died. After living at the facility for 2 years the resident began to wander within the facility. The facility then issued a 2-week eviction notice to the resident stating they could no longer care for her. The facility also increased the resident's monthly fee from approximately \$1,600 to more than \$6,400. The resident moved to another facility.

Contracts A resident contract did not contain all state-required elements, such as the basic daily, weekly or monthly rates, and a list of available services and fees not included in the basic rate.

The CHAIRMAN. I thank you, Ms. Allen.
We now go to Dr. Hawes.

STATEMENT OF CATHERINE HAWES, SENIOR RESEARCH SCIENTIST, MYERS RESEARCH INSTITUTE, MENORAH PARK CENTER FOR THE AGING, BEACHWOOD, OH

Ms. HAWES. Thank you, Mr. Chairman, and good afternoon. I am especially honored to be here because of the extraordinary attention the committee has paid over the last year to long-term care and the well-being of older Americans.

I would like to report the findings from a national study of assisted living for the frail elderly which is being conducted for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. ASPE is releasing that report today at the hearing and copies are available in the back of the room and also on the DHHS home page. Additional support was provided for this project by the Administration on Aging, NIA, AARP, and the Alzheimer's Association.

I would like to emphasize, however, that my testimony represents my opinions and not necessarily those of the sponsoring organizations or my employer, Menorah Park.

We recently completed a national survey of assisted living facilities and these are some of the findings.

We found an estimated 11,500 facilities nationwide with 650,000 beds. Fifty-four percent of the ALFs were free-standing. The rest were on a campus that offered a multiple levels of care, such as nursing home or congregate living. The average facility had 57 beds and an occupancy rate of 84 percent. Nearly all of the ALFs offered basic services such as housekeeping, three meals a day, 24-hour staff, and assistance with medications, bathing, and dressing. Seventy-four percent offered to arrange or provide therapies and some nursing care or monitoring. But only 40 percent had a full-time registered nurse on staff.

We also found what you have all noted, that the average ALF had been in business 15 years, but one-third had been in business no more than five years, so there is a lot of growth in the industry.

What these general descriptive statistics mask, however, is what Senator Grassley spoke of, and that is the enormous variability among assisted living facilities. We found four basic types of assisted living facilities.

The first is what we call low service, low privacy. Most rooms were not private and the facilities offered little beyond help with bathing, dressing, and possibly medications. This type of assisted living facility cannot easily be distinguished from traditional concepts of board-and-care. On the chart, this includes the orange category and the purple one and is 59 percent of the places that call themselves assisted living across the nation.

The next type, the red category, includes 18 percent of the ALFs, and offered a high degree of privacy but low services, what I call a "cruise ship" model of assisted living. Only 19 percent of the ALFs in this model, for example, would provide or arrange nursing care and retain a resident who needed such care.

A third type of ALF, which is green on the chart, offers high service but low privacy. Two-thirds of the accommodations were in

rooms, rather than apartments, and fewer than 80 percent of the rooms were private. But all of these facilities had an RN on staff, and they would retain a resident who needed nursing care. About 12 percent of the ALFs nationwide fall into this category.

The fourth type, indicated by yellow on the chart, is the high privacy, high service ALF. Only 11 percent of the facilities nationwide are in this category.

So we do not really have one thing that is assisted living. We have four different models and variations within them.

Our study is also examining the extent to which the current supply matches the philosophical principles of assisted living, such as privacy. Seventy-five percent of the accommodations were private; 22 percent were semi-private, and two percent shared by three or more individuals in a room. Thirty-five percent of the bathrooms were shared.

In the Oregon model, apartments are considered an essential ingredient of assisted living. However, nationwide, accommodations are pretty evenly split between apartments and rooms, as you can see from that chart.

Another principle is that services should be available to meet residents' scheduled and unscheduled needs. However, it appears that both licensure policies and facility policies limit the ability of facilities to do this. The bottom line here is shown in red, which indicates that 21 percent of the ALFs surveyed would not arrange or provide, either with their own staff or a home health agency, any nursing care, even for a temporary condition like flu.

Finally, we wanted to know whether residents would be able to age in place. We found that 90 percent of the administrators would retain residents whose needs moved from relative independence to moderate physical and cognitive limitations, but 31 percent would not retain a resident who eventually needed to use a wheelchair. Thirty-eight percent would not retain a resident who needed help with walking. Fifty-four percent would not retain a resident who needed help getting in and out of a bed, a chair, or a wheelchair. Fifty-five percent would not retain residents with moderate to severe cognitive impairment. And 76 percent would not retain a resident who exhibited any kind of challenging behavior, such as wandering. Finally, only 28 percent of the ALFs nationwide would retain a resident who needed nursing care or monitoring for more than 14 days.

Finally, we asked whether assisted living was affordable, and that is the last chart that we have. In 1997, nearly two-thirds of persons aged 75 and older had annual incomes below \$15,000 and could not have afforded the most common ALF rate charged by the low service, low privacy facilities.

The high service and high privacy ALFs charged an average annual price, that is the basic price, of \$22,000 per year. That would have been unaffordable for 84 percent of persons aged 75 and older.

I ask that the rest of my remarks be submitted into the written testimony.

[The prepared statement of Ms. Hawes follows:]

***"Shopping for Assisted Living:
What Consumers Need To Make the Best Buy"***

**Hearing of
The U.S. Senate Special Committee on Aging**

**Testimony of
Catherine Hawes, Ph.D.
Senior Research Scientist
Myers Research Institute
Menorah Park Center for the Aging
Beachwood, Ohio**

Washington, DC: April 26, 1999

Good afternoon, Senator Grassley and members of the Committee. Thank you for the opportunity to testify before the Committee and for the extraordinary care and attention the Committee has shown over the last year, indeed over the last three decades, to the well-being of the nation's elders and particularly to issues related to long-term care.

My name is Catherine Hawes, and I am a Senior Research Scientist at the Myers Research Institute at Menorah Park Center for the Aging in Cleveland, Ohio. Twenty-three years ago, I started my career in aging and long-term care as an investigator for this Committee, so I feel especially honored to be here today as a witness.

I am here to discuss research findings from *A National Study of Assisted Living for the Frail Elderly*. I have submitted written testimony and the Executive Summary of a report from this study that present somewhat greater detail on the main points I will make today.

I am the principal investigator and project director for this study, which is being conducted for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE). Additional support for this project has been provided by the Administration on Aging, the National Institute for Aging, the Alzheimer's Association, and the American Association of Retired Persons. ASPE and AARP funded the survey and data analysis that serve as the basis for my testimony; however, my testimony today represents my views alone and does not necessarily represent the views or opinions of DHHS/ASPE, AARP, or Menorah Park.

Recently, project staff completed a telephone survey of a nationally representative sample of assisted living facilities. Project staff surveyed a sample of 2,945 places thought to be assisted living facilities in 34 states. For those places that met study eligibility criteria, project staff conducted a more in-depth survey of the administrators or their designees.¹

Because of our sample design, we are able to provide a description of the assisted living industry, nationwide, as of early 1998. Over the course of the next year, the study will report on site visits to a sample of assisted living facilities and in-depth interviews with residents, family members, staff and administrators. In addition, project staff will conduct follow-up telephone interviews with all residents who have left the facility within eight months of the original interview. If the resident is deceased, we will interview the next-of-kin.

The main goals of the telephone survey were:

- 1) To provide an estimate of the number of assisted living facilities nationwide;
- 2) To describe the characteristics of the assisted living industry,

¹ To be eligible for the study, a place had to meet the following criteria: (1) Serve a mainly elderly clientele; (2) Have more than 10 beds; AND either (3a) Be a facility that holds itself out to be "assisted living" OR (3b) Be a facility that provided at least the following services: 24 hour staff, housekeeping, at least 2 meals a day, and help with at least two of the following: medications, bathing or dressing.

- 3) To examine the degree to which the current supply of assisted living facilities (ALFs) matches the philosophical principles of assisted living; and
- 4) To determine whether assisted living is affordable for low and moderate-income older persons.

One of the questions I hear repeated by consumers and state policy-makers alike is "what is assisted living?" Some of the national statistics from our 1998 survey may help answer this question. For example, we found:

- An estimated 11,500 facilities that met our definition of assisted living, with approximately 650,000 beds.
- The average facility had 57 beds.
- The average facility occupancy rate was 84%.
- 54% of the ALFs were free-standing; 46% were situated on a campus offering multiple levels of care, such as nursing home care, congregate care, or independent living in addition to assisted living.
- The average length of time in business was 15 years, but more than half the industry had been in business for 10 years or less.
- Nearly all ALFs either provided or arranged a number of basic services, including housekeeping, three meals a day, 24-hour staff, medication reminders, and assistance with bathing and dressing.
- About nine out of ten (88%) facilities offer assistance with medications.
- About three-quarters of the ALFs offered to arrange or provide therapies (74%) and some care or monitoring by a licensed nurse (80%).
- 40 percent of the facilities had a full-time registered nurse (RN) on staff.

What these general, descriptive statistics mask is the tremendous variation across the country among places known as assisted living facilities. Any attempt to understand assisted living is hindered by the lack of a common definition of assisted living.

As Dr. Mollica has shown in several of his reports, there is no consensus among state policy-makers about the appropriate regulatory model for assisted living. Similarly, in the market-place, there is no consensus about what assisted living is. Indeed, we found enormous diversity in the size, accommodations, services, staffing, policies on admission and retention, and price among places that called themselves assisted living. Essentially, we identified four different types of ALFs based on their mix of services and privacy.



The most common type of assisted living facility cannot be easily distinguished from traditional board and care homes. A significant proportion of resident rooms were shared rather than private, and such facilities offered little beyond assistance with medications, bathing, or dressing. In about half the ALFs described by this model, there was at least one room shared by three or more people. This model, which we define as minimal or low service/low privacy, represented 58 percent of all the places that described themselves as assisted living.

Another ALF type offers a high degree of privacy in accommodations but low services, a sort of "cruise ship" model of assisted living. In this model, more than 80 percent of the accommodations were private. However, these facilities would have had a difficult time helping residents age in place, since they had no RN on staff and most were unwilling or unable to provide or arrange nursing care for residents. Only 19% of the ALFs in this model would provide or arrange nursing care and retain a resident who needed such care. This ALF type comprised 18 percent of all ALFs nationwide.

A third type of ALF is one we describe as high service/low privacy. In such facilities, two-thirds of the accommodations were in single rooms rather than apartments, and fewer than 80 percent of the rooms were private. However, all such facilities had a full-time RN on staff and about half the facilities (53%) were willing to provide or arrange nursing care, as needed, and retain residents who needed such care. This was also the ALF type that had the most expansive admission and retention criteria and the highest resident acuity. For example, such facilities were more likely to retain residents who needed assistance with transfers in or out of bed or a wheelchair and residents who needed nursing care. Compared to the other ALF types, they also had a much higher proportion of residents who received assistance with three or more activities of daily living (ADLs), such as help with locomotion or using the toilet, as well as bathing and dressing. An estimated 12 percent of the ALFs across the country were in this category.

A fourth type of ALF offered high service and high privacy. Only 11 percent of all ALFs fell into this category. While resident accommodations were almost evenly split between single rooms and apartments, nearly all the accommodations were private. In addition, 41 percent of the high service/high privacy ALFs offered to arrange or provide nursing care and retain residents who needed such care. All had an RN on staff.

Having described ALFs, our next question was whether the current supply of assisted living facilities matched the philosophical principles of assisted living. One philosophical tenet is that residents should have control of their personal environment, often defined, at least partially, in terms of privacy. Certainly, on average, ALF residents had more privacy than residents of board and care and nursing homes. But not all ALFs provided an environment consistent with the principle of privacy.

- Three-quarters of resident accommodations were private; 2 percent were in ward-type rooms that housed three or more residents; and the remainder were semi-private.

- Thirty-five percent of all bathrooms were shared; thus some residents have private rooms but share bathrooms.

In the Oregon model, apartments were also considered an essential ingredient of assisted living; however, nationwide, only 48 percent of all resident accommodations were in apartments; 52 percent were in single rooms.

Another philosophical tenet of assisted living is that services should be available to meet residents' scheduled and unscheduled needs. The answer to whether the current supply of ALFs meets this principle is not yet clear. However, it appears that both facility policies and, in some states, licensure policies limit the ability of ALFs in general to meet the health needs of residents. For example, we asked administrators about their willingness to address a temporary need for nursing care. Slightly more than half the facility administrators (52%) reported that they would provide such care with a registered nurse (RN) or licensed vocational nurse (LVN) from the facility staff. Twenty-five percent reported that they would help the resident arrange for such care with an external agency, such as a home health provider. But slightly more than one in five ALFs (21%) reported that they did not provide or arrange any services by an RN or LVN/LPN. Further, while most facilities would provide or arrange nursing care for a period of 14 or fewer days, only 28% of the ALFs nationwide would retain a resident who needed such care or monitoring for more than 14 days.

We also wanted to know whether residents would be able to "age-in-place," another key element of the philosophy of assisted living. We found that there was a limit to the amount of aging in place that could occur in most ALFs, if aging was accompanied by decline in the resident's physical and cognitive functioning. Nine out of ten administrators reported a willingness to serve residents with modest physical limitations, such as needing help with bathing, dressing, or medications. In addition, 69 percent said they would retain residents who used a wheelchair to get around, while 62 percent would retain a resident who needed help from another person with walking or using a wheelchair.

At the same time, this meant that 31 percent of the ALFs would not retain a resident who eventually needed to use a wheelchair to get around, and 38 percent would not retain a resident who needed any assistance from another person to walk. The majority of ALFs (54%) would not retain a resident whose health declined to the point at which he or she needed assistance with transfers in and out of bed, a chair, or wheelchair. Most facility administrators also reported they would not retain residents with moderate to severe cognitive impairment (55%), and 76 percent were unwilling to retain a resident who exhibited any challenging behaviors, such as wandering. Thus, while most assisted living facilities were willing to admit residents in the early stage of Alzheimer's disease or related dementias, most would not retain such residents as their level of cognitive impairment increased or if they developed a behavioral symptom.

A final issue we wished to explore was whether assisted living was affordable. The most common monthly price was between \$1000 and \$1999 or between \$12,000 and \$24,000 per year. However, it is important to note that the average monthly price was held down

by the presence of a very large number of ALFs that offered minimal or low privacy and services. The most common monthly price for ALFs offering either high service or high privacy was approximately \$1,800 per month or almost \$22,000 per year. Moreover, the basic monthly price did not cover all the monthly expenses in many assisted living facilities, which often impose additional charges for such services as transportation, personal laundry, special diets, and medication administration. Thus, the total cost for residents can be higher than the basic monthly price.

When we examined the price of assisted living and compare it to the income of the elderly, it was clear that most ALFs were not affordable for low and moderate income elderly. In 1997, nearly two-thirds of persons aged 75 and older (64%) had annual incomes below \$15,000 and could not have afforded the most common ALF rate (\$1458 per month/\$17,496 per year) charged by low service/low privacy ALFs. High service (\$22,068) and high privacy (\$21,252) ALFs, at an average cost of about \$22,000, would have been unaffordable for more than four out of five people aged 75 and older.

The implications of these findings for consumers and policy-makers are significant.

1. Because of the substantial differences among places known as assisted living facilities, consumers need to be sophisticated shoppers. They need to understand their own or their relative's current needs and to anticipate the likely trajectory of those needs over time.
2. Consumers and their families should be aware that the promise of aging in place in an ALF is not unlimited. For a substantial number of residents, the move to assisted living will entail a subsequent move to another type of health or personal care facility.
3. In order to facilitate appropriate consumer decision-making, ALFs must provide accurate, comprehensive and comprehensible information to consumers about the staffing, services, and charges, as well as explicit information about their retention policies.
4. With the exception of a very few cases, assisted living, particularly in facilities offering any type of private accommodations or high services, is largely not affordable for moderate and low-income elderly.
5. Policy-makers should beware the assumption that ALFs are substitutes for nursing homes. ALF admission and retention policies, their level and type of staffing, and their unwillingness or inability to address problems common among nursing home residents, such as behavioral symptoms, moderate to severe cognitive impairment, and the need for on-going nursing care or oversight limit their ability to serve the same population.

The CHAIRMAN. Thank you, Dr. Hawes.
Mr. Mollica.

STATEMENT OF ROBERT L. MOLLIKA, DEPUTY DIRECTOR, NATIONAL ACADEMY FOR STATE HEALTH POLICY, PORTLAND, ME

Mr. MOLLIKA. Thank you, Mr. Chairman and members of the committee. It is a privilege to speak with you today about what I believe is one of the most important developments in our long-term care system, and that is the emergence of assisted living.

We conducted two studies that were funded by the Assistant Secretary for Planning and Evaluation and found that there were diverse licensing and reimbursement policies among States. There was also a great deal of flexibility and creativity among the different approaches and States expressed a real interest in promoting a residential consumer centered model for access to long-term care services.

Our study found that 25 States, including Florida and Oregon, have regulations that use the term "assisted living". The remaining States have regulations that apply to assisted living but they do not use the term. State policy is changing very rapidly, and since the GAO study was completed, new regulations were adopted in Oregon and proposed changes have been issued in Florida. Thirty-two States, including Florida and Oregon, cover services in assisted living settings under Medicaid, while coverage is being considered in California and Ohio.

States expressed a great concern about balancing quality of care, consumer preferences, and appropriate oversight. Twenty-two States include a statement of a philosophy of assisted living in their law or regulations. This philosophy supports aging in place and emphasizes home-like settings, consumer control, and autonomy. It is intended to be a very different model from older board-and-care regulations.

States with newer regulations tend to allow facilities to serve residents who need more care than do older rules governing board-and-care. Several States now allow people to live in residential settings who previously could only be served in nursing homes, so long as the facilities have the staffing capacity to serve them.

While this is a welcome development, it also raises expectations and responsibilities. Consumers moving in expect to remain when their health and functional capacity declines and they need more care. Unfortunately, this expectation may not always be realized if the facility decides not to provide the full level of service allowed by State rules or does not have the staff to do it. It is critical that facilities clearly disclose to prospective residents the services they provide and the circumstances under which a person may have to move.

State regulations include requirements for residency agreements or contracts with residents. Several elements are common: The services provided, the monthly fee, the additional services available, the cost of these services, resident rights, and the circumstances under which residents may have to move. Unfortunately, not all States include the same requirements and how well they are implemented varies also from State to State.

State leaders are also concerned about affordability and several surveys have found that over 50 percent of the assisted living facilities charge a monthly fee for private pay residents that is \$2,000 a month or lower. This is very affordable for State Medicaid programs and well below the cost of a nursing home, and although the number of Medicaid beneficiaries living in assisted living is low, States do have the tools to make it affordable.

Since Medicaid cannot pay for room and board outside a hospital or a nursing home, some residents may not have enough income to pay these costs and State supplements to the SSI payment may be needed here. Using Medicaid waivers, States can serve older people with income up to \$1,500 a month and States have the flexibility under these waivers to allow residents to keep enough of the income to pay for room and board while Medicaid pays for the services.

There are also some new programs that are emerging to create affordable assisted living. The Robert Wood Johnson Foundation has funded the National Cooperative Bank Development Corporation to develop affordable models using tax credits and tax-exempt bonds, and the proposed HUD budget would convert some 202 projects to assisted living using Section 8 vouchers in these settings.

As assisted living grows, States face enormous challenges to promote diversity in choice, to make it affordable, to promote quality, and to develop appropriate and effective oversight strategies that value consumer preferences and focus on outcomes. These are not easy challenges. State policy makers want to avoid repeating the negative perception often associated with nursing homes, that is, cookie cutter designs, institutional settings, over-medicalized services, and loss of privacy, dignity, and independence.

Yet, developing an outcome oriented, consumer focused regulatory and oversight system is not easy, but States, I believe, are the laboratories where change can be tested and States welcome this challenge. They are committed to creating a system that offers consumers real choices and to ensuring that their choices will be supported with appropriate oversight to ensure that services are of the highest quality. Thank you.

[The prepared statement of Mr. Mollica follows:]

Extended remarks

Robert L. Mollica, Ed. D.
Deputy Director

National Academy for State Health Policy
Portland, Maine

Before

Senate Special Committee on Aging

April 26, 1999

Mr. Chairman and members of the Committee, it is a privilege to speak with you today about what I believe is one of the most important developments in our nation's long term care system - the emergence of assisted living. I also want to commend Senator Wyden and the General Accounting Office for initiating a review of two critical aspects of assisted living: quality of care and consumer expectations.

With funding from the Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, the National Academy for State Health Policy (NASHP), conducted two studies of state assisted living licensing and Medicaid reimbursement policy. NASHP is a non-profit organization, based on Portland Maine, that was formed to help states learn from one another and to provide a forum for state officials to work together in a multi-disciplinary, cross agency manner on health and long term care issues. The results of the studies highlight the diversity among states, the flexibility and creativity of approaches, and the interest of states in promoting a residential, consumer-centered model for accessing long term care services.

GAO studied four states: California, Florida, Ohio and Oregon. Our study found that 25 states, including Florida and Oregon, have regulations with an assisted living category. The remaining states do not use the term but some, like Ohio, have updated their rules. Since the GAO study was completed, new regulations were adopted in Oregon and proposed changes were issued in Florida. Thirty-two states, including Florida and Oregon, cover services in assisted living settings under Medicaid while coverage is being considered in California and Ohio.

Philosophy

States are very concerned about balancing quality of care, consumer preferences and appropriate oversight. Assisted living in many states represents a more consumer-focused model which organizes the setting and the delivery of service around the resident rather than the facility. States which emphasize consumers use terms such as independence, dignity, privacy, decision-making, and autonomy as a foundation for their policy. Statutes, licensing regulations, and Medicaid requirements in 22 states, up from 15 states in 1996, contain a statement of their philosophy of assisted living. States which have adopted or proposed this philosophy are Arizona, Delaware, Florida, Hawaii, Illinois (demonstration program), Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Nebraska, New Jersey, New Mexico, Oregon, Rhode Island, Utah, Vermont, Virginia, Washington and West Virginia. Massachusetts includes their language in a section that allows the Secretary of Elder Affairs to waive certain requirements for bathrooms as long as the residences meet the stated principles.

Oregon's definition states that: "Assisted living promotes resident self-direction and participation in decisions that emphasize choice, dignity, privacy, individuality, independence and home-like surroundings." Florida's statute states the purpose of assisted living is "to promote availability of appropriate services for elderly and disabled persons in the least restrictive and most home-like environment, to encourage the development of facilities which promote the

dignity, individuality, privacy and decision-making ability...." The laws also state that facilities should be operated and regulated as residential environments and not as medical or nursing facilities. The regulations require that facilities develop policies which allow residents to age-in-place and which maximize independence, dignity, choice, and decision-making of residents.

New Jersey amended its rules to emphasize the values of assisted living and introduce managed risk. Facilities must provide and coordinate services "in a manner which promotes and encourages assisted living values." These values are concerned with the organization, development, and implementation of services and other facility or program features so as to promote and encourage each resident's choice, dignity, independence, individuality, and privacy in a home-like environment. The values promote aging-in-place and shared responsibility.

Although the philosophy of assisted living is increasingly found in state policy, facilities must take additional steps to operationalize it. Aspects of assisted living that might be considered to convert philosophy to action include the living units required or provided, whether living units may be shared by choice, use of a shared-risk process to develop a service plan and training for facility staff on the principles of assisted living. Eight of the twenty-two states with a statement of the philosophy of assisted living also require apartment units. Rules in four states have mixed requirements, allowing bedrooms in some arrangements and apartments in new construction. Fifteen of the states allow sharing (apartments or bedrooms) only by choice of the residents. Ten states use a shared risk process for developing tenant service agreements or service plans. Connecticut, which licenses assisted living service agencies and not facilities, does not have a statement of philosophy, but residences must offer apartments, and sharing is allowed only by choice. Two other states, Ohio and Oklahoma, have a shared-risk provision and no statement of philosophy. Four states include a philosophy of assisted living but do not address the remaining areas which would operationalize the philosophy. Eleven states require that the training curriculum for staff must cover the principles of assisted living.

Occupancy

States with newer regulations tend to allow facilities to serve residents who need more care than under older board and care rules. Several states now allow people to live in residential settings who previously could only be served in nursing homes as long as the facilities have the staffing capacity to serve them. The broadest policies have been developed in Arizona, Delaware, Kansas, Maine, Nebraska, New Jersey, and Oregon. Draft rules in Hawaii and Vermont also allow facilities to serve higher acuity residents. Florida has a list of conditions that residents in Extended Congregate Care settings may or may not have and in Ohio, residents needing part time or intermittent nursing care may remain for 120 days.

State regulations set the parameters governing who may be served, but they allow facilities themselves to determine whom they will serve within those parameters. This flexibility may cause confusion among consumers who are aware of the state's regulations and might expect to receive care as their needs increase yet find the facility's policy may not allow residents

with certain conditions to remain.

Policies governing occupancy can be grouped in five areas: general statements, health related conditions, functional measures, Alzheimer's disease and dementia and behavior. Rules in many states specify a list of prohibited conditions. Other states require that tenants have stable and predictable health conditions. A few states limit the number of days residents with certain health care needs may be retained. Regulations may also include a combination of these approaches.

Resident agreements

Including a philosophy of assisted living and allowing residents to receive a higher level of care support aging-in-place. While this a welcome development, it is also raises expectations. Consumers move into a facility expecting to remain when their health or functional capacity declines and they need more care. Unfortunately, this expectation may not be realized if the facility decides not to provide the full level of service allowed by state rules. State rules usually set the parameters for admission and retention while owners themselves set the policy for their facility. It is critical that facilities clearly disclose to prospective residents the services they provide and the circumstances under which a person may have to move to another setting.

State regulations include requirements for the residency agreements or contracts with residents. There are several common elements – the basic services provided, the monthly fee for the basic service package, additional services available, the cost of these services, resident rights and the circumstances under which residents may have to move.

The agreements include a description of the fee or charges to be paid, the basis of the fee or what is covered, who will be responsible and the method, and time of payment. Refund policy is also covered by agreements in many states. Rules covering agreements specify the amount of advance notice tenants must be given when rates are changed. A thirty-day notice is usually required. Policies governing the management of resident funds, when applicable, may also be included in resident agreements.

Service provisions generally describe the services to be provided that are covered by the basic fee and any additional services that might be available. Maryland's rules require disclosure in the agreement of the level of care that the facility is licensed to provide and the level of care needed by the resident at the time of admission. Wisconsin requires that the qualifications of staff who will provide services are included in the agreement and whether services are provided directly or by contract. The resident agreement in Colorado includes a care plan which outlines functional capacity and needs.

Resident rights and the provisions that allow staff to inspect living quarters, with the resident's permission, are also required by some states. Other states require that a copy of residents' rights provisions must be provided to each resident, without including it as part of the

resident agreement. Grievance procedures may also be included in the agreement or provided separately to residents.

Terms of occupancy may also address provision of furnishings and the policy concerning pets. Other terms often include admission policy and descriptions of the reasons for which a resident may be involuntarily moved as well as the time frame and process for informing the resident and arranging for the move. Policies concerning shared occupancy must be included in agreements under Maryland's rules as well as procedures which will be followed when a resident's accommodations are changed. The changes could be due to relocation, change in roommate assignment, or an adjustment in the number of residents sharing a unit. Agreements may also include the facility's "bed hold" policy when residents temporarily enter a hospital, nursing home, or other location.

Agreements in Colorado must disclose whether the facility has an automatic sprinkler system. Rules in Maine do not allow the resident agreement to contain any provision for discharge which is inconsistent with state rules or law or imply a lesser standard of care than is required by rule or law. Agreements in Maine must also include information on grievance procedures, tenant obligations, resident rights, and the facility's admissions policy.

Kansas requires that citations of relevant statutes and copies of information on advance medical directives, resident rights, and the facility's grievance procedure must be given to residents before an agreement is signed.

Kansas specifies that the agreement must be written in clear and unambiguous language in 12 point type. Draft rules in Maryland direct that the agreement must be a clear and complete reflection of commitments agreed to by the parties and the actual practices that will occur in the facility. The language must be accurate, precise, easily understood, legible, readable, and written in plain English. Wisconsin's rules require that the format of agreements make it easy to readily identify the type, amount, frequency, and cost of services.

Most state rules do not address revising or updating resident agreements. However, Alabama includes the period covered by the agreement. Wisconsin's rules provide that agreement must be reviewed and updated when there is a change in the comprehensive assessment, or at the request of the facility or the resident. Updates are otherwise made as mutually agreed by the parties.

Negotiated risk

Sixteen states have adopted or proposed a negotiated risk process to involve residents in care planning and to respect resident preferences which may pose risk to the resident or other residents. Agreements are typically developed as a joint effort between the resident, family members (when appropriate), the case manager, and facility staff. The purpose of this process is to define the services that will be provided to the resident with consideration for preferences of

the resident as to how services are to be delivered. The agreement lists needs and preferences for a range of services and specific areas of activity under each service. To many regulators, negotiated service agreements operationalize a philosophy that stresses consumer choice, autonomy, and independence over a facility-determined regimen that includes fixed schedules of activities and tasks that might be more convenient for staff and management of an efficient "facility." It places residents' needs and preferences ahead of the staff and administrators and helps turn a "facility" into a home.

Oversight

States rely on several strategies to monitor quality: training requirements, background checks, regular inspections and complaints. Several states have developed additional staffing, disclosure and training requirements for facilities serving residents with Alzheimer's disease. Case managers in Medicaid home and community based services waiver programs also monitor quality for Medicaid beneficiaries.

New approaches are likely to emerge to promote quality. Our survey identified 17 states that were interested in developing outcome measures for assisted living. Although the interest is high, much work needs to be done. Developing outcome measures requires collection of data and devising measurable indicators for people with chronic conditions. Two states, Maine and Vermont, will collect data from which such measures might be developed. Officials in Washington developed a review guide for inspectors that is intended to monitor quality of care and how the philosophy of assisted living is being implemented. Facility quality improvement programs are required under rules in Connecticut and draft rules in Vermont.

Affordability

Many state leaders are concerned about affordability. Several surveys have found that over 50% of the assisted living facilities charge a monthly fee for private pay residents that is \$2,000 a month or lower. This is very affordable for state Medicaid programs and well below the cost of a nursing home.

By early 1999, 32 states covered services in residential settings, either assisted living or board and care licensing categories, through Medicaid. Coverage is planned in the District of Columbia, Hawaii and Utah while Connecticut and Louisiana are implementing demonstration programs. Nebraska has implemented a grant program to facilitate conversion of excess nursing home capacity to assisted living and other community based alternatives.

States typically use the Home and Community Based Services Waiver (1915 (c)) to finance care, however, regular state plan services are used in five states. The basis of coverage is important. There are important differences between waiver services and state plan services. Waiver services are available only to Medicaid beneficiaries who would be eligible to enter a nursing home if they applied. This test is not required for beneficiaries using state plan services.

States set limits on the funds that can be spent through waiver programs while state plan services are entitlements. Under waivers, states may use the optional eligibility category under home and community based waiver service programs that allows beneficiaries with incomes less than 300% of the federal SSI benefit (\$1500 a month in 1999), to be eligible and receive all Medicaid services. In the absence of this provision, people who live at home and have too much income to qualify for Medicaid would be forced to enter a nursing home and quickly "spend down" their income and assets to qualify. Using this option, states can pay for services in assisted living settings and other in-home and community services to give people options to nursing home admission. Residents pay for the room and board costs and Medicaid covers the services.

In addition, new programs are emerging to create affordable assisted living using tax credits and tax exempt bonds. The Robert Wood Johnson Foundation has funded the NCB Development Corporation to develop affordable assisted living using these and other mechanisms. The proposed HUD budget would convert some 202 projects to assisted living and use Section 8 vouchers in these settings.

Challenges facing States

As assisted living grows, states face enormous challenges to promote diversity and choice, to make it affordable, to promote quality, and to develop appropriate and effective oversight strategies that value consumer preferences and focus on outcomes. These are not easy challenges. As I talk to state policy makers, they often say they want to avoid the experience with nursing homes, and strategies that produce cookie cutter designs, institutional settings, over-medicalized services and loss of privacy, dignity and independence. Developing an outcome oriented, consumer-focused regulatory and oversight system is not easy. However, states are the laboratory where change can be tested. States welcome this challenge. They are committed to improving our long term care system, to creating a system that offers consumers real choices and to ensuring that the choices will be supported with appropriate oversight to ensure that services are of the highest quality.

Thank you.

Resident agreement provisions National Academy for State Health Policy				
Provision	CA	FL	OH	OR
Terms of occupancy				✓
Basic rate	✓	✓	✓	✓
Cost of additional services	✓	✓		✓
Deposits/fees		✓	✓	✓
Refund policy		✓	✓	✓
Billing and payment method, due dates	✓	✓		✓
Notice of change in rates	✓	✓	✓	✓
Accommodations		✓		
Basic services available	✓	✓		✓
Additional services available	✓	✓	•	✓
Service planning process				✓
Philosophy				✓
Resident rights and responsibilities		✓	•	✓
System for packaging medications				✓
Move out/evictions policy		✓		✓
Bed hold policy		✓		
Staffing plan				✓
Visiting policy	✓			
Policy on advance directives			•	
Smoking policy				
General facility policies	✓			
State authority to review records	✓			
State of religious affiliation, if any		✓		

- Facilities in Ohio must provide this information prior to or upon admission but it is not part of the resident agreement.

The CHAIRMAN. Thank you.
Ms. Hannum.

**STATEMENT OF CINDY HANNUM, ASSISTANT ADMINISTRATOR,
SENIOR AND DISABLED SERVICES DIVISION, OREGON DEPARTMENT OF HUMAN SERVICES, SALEM, OR**

Ms. HANNUM. Thank you, Mr. Chairman. I am very pleased to be here. I am going to shorten my comments in the interest of time, but I think it is important to note that our agency is one that is both the State unit on aging, the State Medicaid long-term care payer, and the overall regulatory agency. So in our public policy, we have tried very hard to have good standards for care and to actually develop lots of choices for seniors.

One of these choices, of course, are Assisted Living Facilities, which in Oregon is a very specific model where there is privacy, dignity, individual units, bathrooms that are private, flexible services, and they do promote aging in place. Actually, this has been a very, very popular model. We started with seven in 1990 and we expect by the end of 1999 to have about 130. This is a choice for the private consumer. Over 70 percent of the residents in ALFs are, in fact, private paying.

Now, this leads us to regulatory oversight, and we found back in 1996 that we were not able to keep up with all of the regulatory oversight, so we decided on a course of action that had several issues to it. One, we were going to rewrite the rules. The rules are the foundation for good services and care and we have added several things to strengthen the benefits for the residents.

We have a bill of rights, consumer bill of rights. We have all kinds of things that have to be put into resident contracts that deal with explaining services, explaining costs, and so forth. We have dealt with the issue of aging in place by talking about scope of service. Aging in place is a very confusing concept, so we have decided to say what the floor is going to be for services. Oregon is not a State that asks people to leave residential environments just because the needs change.

We have also strengthened R.N. consultation requirements. These models deal with chronic care. Chronic care means that we have to wed the services of personal care with health care oversight, and we believe through RN delegation of care, we are able to do that effectively.

We have increased training requirements for staffing and we have emphasized adequate staff to meet the residents' needs. Oregon does not prescribe minimum staffing standards, but rather expects that, based upon the changes in care needs, staffing will be increased.

Along with the increased standards, we have changed the survey process. We think survey and inspection, both on an annual basis and more frequently as needed, is extremely important. We also have an investigation process for any type of consumer complaints. All of these things coupled together give the best chance to see what the actual facility care is like through the eyes of the residents.

We have also strengthened sanction tools. Now, all of these things in terms of regulatory compliance are very important, but

on the other hand, we have to do education and training for providers and they have to work on their own internal quality systems. Indeed, we have had a wake-up call, Senator Wyden, because of the rapid growth of these facilities. With the combined approaches, we believe we have a better chance to improve services for seniors and others who are in these living environments.

We believe that States should be the best keeper of regulation because of all of the diversity that is available, but we would welcome Federal input for best practices and information sharing and issues such as improving the availability of nurse delegation throughout the country to give States information about how that might be done effectively.

With that, I will conclude and be happy to answer questions. Thank you.

[The prepared statement of Ms. Hannum follows:]

Statement by
Cindy Hannum, Assistant Administrator
Senior and Disabled Services Division
Oregon Department of Human Resources
on
"Shopping for Assisted Living:
What Consumers Need to Make the Best Buy"
before the
Senate Special Committee on Aging
April 26, 1999

We are pleased to have the opportunity to testify before this committee on the subject of assisted living. As you know, in 1997 Oregon was one of four states researched by the U.S. General Accounting Office (GAO) for its report on assisted living. An independent program review is often very instructive and we openly shared information with GAO as it reviewed our policies and program.

Community Based Care Development

Oregon takes great pride in being the first state to forge a partnership with the federal government to give greater independence, dignity and a higher quality of life to members of its senior and disabled population. In 1981, Oregon became the first state to receive a federal waiver to permit use of Medicaid dollars to deliver care to people in community-based settings. We encourage the development of home and community-based care, responding to seniors' preference for greater choice and independence. Many other states have subsequently developed these options in various forms, and we have seen consistent growth in alternatives to nursing facility care.

Oregon consumers want a variety of community-based care options if they are no longer able to remain in their own homes. We have met that challenge through a variety of services and licensed residential care options, including small adult foster homes in residential neighborhoods, larger residential care facilities, and assisted living facilities. (See Appendix B for a list of Oregon's long-term care options).

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The impact of community based care alternatives for consumers has been so significant that, contrary to national trends, Oregon's nursing facility population is declining. We believe Oregon may be the only state in the nation with fewer people in nursing homes today than 10 years ago. Some Oregon nursing facilities are closing due to low occupancy. In order to remain viable, many of Oregon's nursing facilities are doing more short term, post hospital nursing and rehabilitation, or designing services to deliver specialized care for highly impaired individuals. In Oregon today, between 75 and 80 percent of Medicaid long-term care clients are served in a variety of home and community-based care settings.

The concept of community-based care has received a bipartisan embrace in Oregon. It was introduced to Oregonians by a Republican Governor and a Democratic Legislature, with the support of senior advocates such as Senator Wyden. It continues to enjoy bipartisan support because we are providing options consumers want at costs far less than institutional care.

Recent cost data show the average monthly cost for an Oregon Medicaid client (provider payments, client contributions and state staff expenses):

Nursing Facilities	\$2873
Assisted Living Facilities	1937
In-Home Services	1422
Residential Care Facilities	1403
Adult Foster Homes	1241

Profile of Assisted Living Residents

Assisted living has been very popular with Oregon Seniors. More than 70 percent of residents of assisted living facilities are paying with private funds. The average age of residents is 82 years, which is older than adult nursing facility residents (80). Residents also have substantial impairment, needing assistance with one or multiple activities of daily living such as dressing and grooming, bathing, toileting, mobility or eating. Many residents also have some degree of cognitive impairment. Well over half of the Medicaid eligible residents are fully dependent in some activities of

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daily living. This truly has become a nursing home replacement model for Oregon.

Assisted Living Facility Development

The Oregon model of assisted living developed in the late 1980's through a collaborative effort of consumer advocates, providers, and Senior and Disabled Services Division (SDSD) to meet consumer requests for new designs in residential living facilities. The model was designed to allow "aging in place," where needed services are added, increased or adjusted to meet individual's needs as they age. Consumers did not want to have to move from one care setting to another as their frailty, and needs for service, increased.

From the first rule adoption in 1989, assisted living facilities in Oregon have been licensed as 24 hour care settings. Services are required to be provided in private apartments that are disability accessible, with private baths. Services provided are flexible, but are expected to support a resident's independence, choice, individuality and privacy.

The growth of assisted living facilities in Oregon has been dramatic. Seven facilities were in existence in 1990. Now there are 106. Seventy-six (76) new facilities opened in the last four years and we project another 29 facilities will open during 1999. In spite of this growth, we do not think that we are approaching marketplace saturation and we expect to see growth continue through at least 2001, in both rural and urban Oregon.

As we watched the growth of assisted living in Oregon, we realized that the resources provided for regulatory oversight were not sufficient and were not keeping pace with growth in the industry. At that time, our staff resources were directed almost exclusively at licensing and not nearly enough on operational oversight. Consequently, in 1996 we began taking steps to address this imbalance. We approached the problem in three ways.

- We embarked on a process to rewrite state administrative rules for assisted living programs.

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- We expanded staff time devoted to facility monitoring and inspection.
- We focused on improving provider and consumer education.

Rewrite of Administrative Rules

Oregon's administrative rules for assisted living facilities were originally developed in 1989. These original rules did a good job of describing the model and philosophy of assisted living as conceptualized in Oregon. They strongly promoted consumer values such as independence, privacy, and choice. They established facility environmental standards and espoused the principle of the facility providing for the care needs of the resident as their needs changed with age. However, these original rules were not very specific in some areas. Our experience since 1989 has taught us that more specificity was necessary to help providers understand the requirements and to support consumers.

Oregon has a tradition of being inclusive when anticipating major changes in administrative rules. Consequently, in early 1997 when we assembled a committee to revise the rules for assisted living, the committee was composed of senior advocates, industry representatives, Area Agencies on Aging (AAA) and Senior and Disabled Services Division (SDSD) staff.

The committee reviewed the program design, standards of care and services, consumer advocacy issues and the challenges faced by providers in adjusting to consumer needs. This process resulted in major revisions to our rules which went into effect on April 1, 1999. The process of revising the rules was a lengthy, but extremely beneficial process. The new rules strengthen consumer rights, clarify expectations for addressing chronic care needs, and, in general, offer more guarantees for Oregon consumers of assisted living services.

Major improvements in the rules include:

- the addition of a consumer bill of rights that specifies 16 areas in which consumers are protected, including being treated with dignity and respect, having informed choices, privacy, access to records, and the ability to voice grievances.
- expanded requirements for what the facility must disclose to the consumer prior to admission.
- strengthened resident protections for situations in which a facility requests that a resident move out.
- clarification of facility responsibility for meeting the care needs of residents as their needs change over time.
- abuse reporting requirements for staff.
- establishing the use of Oregon's Nurse Practice Act as the standard for provision of health care services.
- increased training requirements for facility administrators and direct care staff.
- requirements for facility quality improvement programs.
- additional regulatory authority to prescribe staffing levels if a facility fails to meet resident needs.

In recent months, we have conducted training sessions throughout the state for providers, SDDS and AAA staff and consumer advocates to explain the new rule requirements and why they are important. We are also offering technical assistance to providers to assist them to make any needed changes to come into compliance.

Expanded Facility Monitoring and Inspection

In addition to rule changes, we have greatly strengthened our monitoring process to improve our oversight of the facilities. Monitoring teams do unannounced inspections annually and additional inspections may be triggered at other times by complaints of poor care. We require facilities to submit plans of correction when we identify deficiencies and have increased our sanction activity for poor performers and when there is harm to a resident or great risk to residents.

Since facilities are now operating under the new rules, our inspection process is also changing to incorporate the new requirements. Some of the changes we are making include: evaluating each facility's ability to deploy sufficient staff to respond to the acuity level of residents in that facility; evaluating consumer satisfaction; and determining whether the facility is evaluating consumer satisfaction.

Oregon continues its long history, under state law, of conducting investigations of individual complaints of abuse or neglect in all licensed care settings. Local SDSD and AAA staff respond to these complaints in their communities under very tight time frames. Investigation findings are coordinated with inspection activity and may result in SDSD sanctions. In addition, case managers visit Medicaid clients in assisted living facilities, providing additional opportunities to identify potential problems.

In Oregon, the Long Term Care Ombudsman program is also active in assisted living facilities, offering consumer advocacy, informal monitoring and complaint resolution. This important service helps promote quality, resolves problems for consumers, and refers significant issues to SDSD for further action.

The message from Oregon is that we consider assisted living facilities a valuable resource for Oregonians. We have learned from experience and improved the level of support for these facilities and the degree to which we monitor them. These improvements reflect a continued commitment in Oregon to support improvements in the quality of life and quality of care that Oregonians receive in long term care settings.

Other Improvements

Oregon will also continue to promote other health care practices, such as nurse delegation, that allow a nurse to teach and support a lay care giver in a community setting. Oregon has a progressive Nurse Practice Act that allows a registered nurse to train and oversee lay care givers who deliver a variety of services that, in most parts of the country, can only be performed by a nurse. Such nurse teaching strengthens care giving systems and allows care to occur where people want to live—in residential settings such as assisted living facilities.

Oregon has learned that to support chronic care in community settings, we need to strengthen coordination between health and community-based care settings. This includes educating the medical community about supporting elderly and disabled persons in the setting of their choice. Education is important for consumers as well; to help them make the best choices of care settings to meet their needs and help them be strong advocates for their care in those settings.

We are confident the changes we have enacted, and the ongoing commitment of provider associations and advocates to work with us, will continue to improve the quality of life for Oregon's assisted living residents.

Although Oregon's regulation of assisted living facilities has changed dramatically since the GAO gathered data for its report, we look forward to the opportunity to carefully review the full report in hopes of discovering ideas and perspectives that can further improve services for Oregonians.

ASSISTED LIVING FACILITIES

ADMINISTRATIVE RULES

Effective April 1, 1999



Department of Human Resources
Senior and Disabled Services Division

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DEPARTMENT OF HUMAN RESOURCES
SENIOR AND DISABLED SERVICES DIVISION

OREGON ADMINISTRATIVE RULES
Chapter 411, Division 056

ASSISTED LIVING FACILITIES

411-056-0000 Purpose

- (1) The purpose of these rules is to establish standards for assisted living facilities. The standards support the concept of aging in place and promote the availability of appropriate services for elderly and disabled persons in a home-like environment which enhances the dignity, independence, individuality, privacy, choice and decision making ability of the resident.
- (2) Assisted living requires the facility to address standards in the delivery of services to residents and design the physical environment to support dignity, independence, individuality, privacy, choice, and decision making abilities of individual residents.

411-056-0005 Definitions

For the purpose of these rules, authorized under ORS 443.400 - 443.460 and 443.991, the following definitions apply:

- (1) "AAA" means a Type B Area Agency on Aging (AAA) which is an established public agency within a planning and service area designated under Section 305 of the Older Americans Act which has responsibility for local administration of Division programs. For the purpose of these rules, the AAAs contract with the Division to perform specific activities in relation to licensing assisted living facilities including: conducting inspections and investigations regarding protective service, abuse monitoring, and making recommendations to the Division regarding assisted living license approval, denial, revocation, suspension, non-renewal and civil penalties.
- (2) "Abuse" means:
 - (a) Any physical injury to a resident caused by other than an accident. Physical injuries include injuries that a reasonable and prudent person would be able to prevent such as hitting, pinching or striking, or injury resulting from rough handling;
 - (b) Neglect, which results in physical harm or discomfort or loss of human dignity. Neglect includes failure to provide agreed upon care or services to a resident, failure to make a reasonable effort to assess what care is necessary for the well-being of the resident, or failure to provide a safe and sanitary environment;
 - (c) Sexual contact, including fondling of a resident by an employee, agent or other resident by force, threat, duress or coercion, or sexual contact with a resident who has

no ability to consent;

- (d) Financial exploitation which includes illegal or improper use of a resident's resources or personal property for the personal profit or gain of another person; borrowing resident funds; spending resident funds without the resident or their designee's consent or if the resident is not capable of consenting; spending resident funds for items or services from which the resident cannot benefit or appreciate; or spending resident funds to acquire items for use in common areas when such purchase is not authorized by the resident;
 - (e) Verbal abuse, including the use of oral, written or gestured communication to a resident, or to a visitor or staff about a resident within that resident's presence, that describes the resident in disparaging or derogatory terms;
 - (f) Mental abuse including humiliation, harassment, threats of punishment or deprivation directed toward the resident;
 - (g) Corporal punishment;
 - (h) Involuntary seclusion of a resident for convenience of staff, or discipline; or
 - (i) Using restraints, except when a resident approves or requests the use of the restraint as a supportive or enabling device to increase independence; or when a resident's actions present an imminent danger to self or others and only until appropriate action is taken by medical, emergency, or police personnel.
- (3) "Activities of Daily Living (ADL)" are tasks usually performed in the course of a normal day in an individual's life which include; eating/nutrition, dressing/grooming, bathing/personal hygiene, mobility, toileting, and behavior management.
- (a) "Independent" means the resident can perform an ADL task without assistance of another person or needs minimal reminding.
 - (b) "Assistance" means the resident can perform some portions of a task independently but requires assistance or supervision with other portions of the task. Assistance ranges from supervision to physical performance of one or more portions of a task.
 - (c) "Dependent" means the resident is dependent on another person to perform all portions of a task. The person does not perform any part of the ADL even with mechanical aids; or the person would perform the ADL task, but has been ordered not to by a physician.
- (4) "Aging in Place" refers to a philosophical approach to care and services which advocates for a person to remain in his/her living environment (home) despite the physical and/or mental decline that may occur with the aging process. For aging in place to occur, needed services are added, increased or adjusted to compensate for the physical and/or mental decline of the individual.

- (5) "Applicant" means the person who completes an application for a license and is the owner of the business.
- (6) "Assisted Living" means a program approach, within a prescribed physical structure, which provides or coordinates a range of supportive personal and health services, available on a 24-hour basis, for support of resident independence in a residential setting. Assisted living promotes resident self direction and participation in decisions that emphasize choice, dignity, privacy, individuality, independence, and home-like surroundings.
- (7) "Choice" means a resident has viable options which enable the resident to exercise greater control over his/her life. Choice is supported by the provision of sufficient private and common space within the facility to provide opportunities for residents to select where and how to spend time and receive personal assistance.
- (8) "Department" means the Department of Human Resources.
- (9) "Dignity" means providing support in such a way as to validate the self-worth of the individual. Dignity is supported by designing a structure which allows personal assistance to be provided in privacy and delivering services in a manner that shows courtesy and respect.
- (10) "Direct Care Staff" means an employee who provides service and assistance to residents including activities of daily living and medication tasks.
- (11) "Disclosure" means the written information prepared by the facility which must be provided to prospective residents and if requested to their family, prior to signing a move-in agreement and at any time after admission if the facility makes any changes in the information.
- (12) "Division" means the Senior and Disabled Services Division of the Department of Human Resources.
- (13) "Exception" means a written variance from a regulation or provision of these rules.
- (14) "Facility" means the licensed physical structure, the licensed owner of the assisted living facility and each entity with which the business owner leases the business directly or indirectly, or contracts directly or indirectly, to manage overall operation of the assisted living facility.
- (15) "First Payor" means policy of insurance, or benefits from Veterans Administration, Medicare, Medicaid, Long Term Care insurance or other payor source.
- (16) "Home" means a living environment which creates an atmosphere supportive of the resident's preferred lifestyle. Home is also supported by the use of residential building materials and furnishings.
- (17) "Independence" means supporting resident capabilities and facilitating use of those abilities. Independence is supported by creating barrier-free structures and careful design

of assistive devices.

- (18) "Individuality" means recognizing variability in residents' needs and preferences and having flexibility to organize services in response to those needs and preferences.
- (19) "Licensee" means the individual, firm or partnership, association, or corporation who applied for, and was issued a license and whose name is designated as owner on the license.
- (20) "Managed Risk" means a process by which a resident's high-risk behavior or choices are reviewed with the resident. Alternatives to and consequences of the behavior or choices are explained to the resident and the resident's decision to modify behavior or accept the consequences is documented.
- (21) "Modified Special Diet" means a diet ordered by a physician or other licensed health care professional that may be required to treat medical conditions (i.e., heart disease or diabetes). These diets include small frequent meals, no added salt, reduced or no added sugar and simple textural modifications. Medically complex diets are not included.
- (22) "Nursing Care" means the practice of nursing as governed by ORS Chapter 678 and Administrative Rules adopted by the Oregon State Board of Nursing in OAR Chapter 851, Division 047.
- (23) "Personal Incidental Funds (PIF)" means the monthly amount allowed each Medicaid and General Assistance resident for personal incidental needs. For the purpose of these rules, personal incidental funds include monthly payments, as allowed, and previously accumulated resident savings.
- (24) "Privacy" means a specific area and/or time over which the resident maintains a large degree of control. Privacy is supported by designing living space which is not shared with others, except by personal choice, and by services that are delivered with respect for the resident's civil rights.
- (25) "Psychoactive Medications" means medications used to alter mood, level of anxiety, behavior or cognitive processes. This term includes antidepressants, antipsychotic, sedatives, hypnotics, and antianxiety medications.
- (26) "Resident" means any individual residing in a unit within an assisted living facility.
- (27) "Restraint" means any physical device that the resident cannot manipulate which is used to restrict movement or normal access to the resident's body.
- (28) "Service Plan" means a written plan for services developed by a service planning team and the resident, or the resident's legal representative, which reflects the resident's capabilities, choices and if applicable, measurable goals and managed risk issues. The plan defines the division of responsibility in the implementation of the services.
- (29) "Service Planning Team" means two or more individuals who assist the resident in

determining what services/care are needed, preferred, and will be provided to the resident.

- (30) "Services" means supervision or assistance provided in support of a resident's needs, preferences and comfort, including health care and activities of daily living, that help develop, increase, maintain, or maximize the resident's level of independent, psychosocial and physical functioning.
- (31) "SDSD" means the Senior and Disabled Services Division of the Department of Human Resources.
- (32) "Unit" means an individual living space constructed as a completely private apartment, including living and sleeping space, kitchen area, bathroom and adequate storage areas.

411-056-0008 License/Contract

To operate and be designated as an assisted living facility, the facility must be licensed as an assisted living facility and comply with OAR Chapter 411, Division 056.

(1) Licensing Requirement

- (a) No person or governmental unit acting individually or jointly with any other person or governmental unit shall establish, maintain, conduct, manage or operate an assisted living facility without being duly licensed.
- (b) The Administrator of the Senior and Disabled Services Division or his/her designee shall determine whether an assisted living facility license is required in cases where the definition of a facility's services is in dispute.

(2) Application Process

Application for a license accompanied by the required fee shall be made to Senior and Disabled Services Division upon forms provided by the Division and shall include full and complete information as to the:

(a) Identity of:

- (A) Each officer and director of the corporation if organized as a corporation;
- (B) Each general partner if organized as a partnership or limited liability partnership;
and
- (C) The governing body if the facility is a government owned facility;
- (b) Name of the administrator of the facility;
- (c) Physical location (address), mailing address, and telephone number of the facility;

- (d) Maximum number of residents at any one time;
 - (e) Maximum number of units;
 - (f) Policies and procedures consistent with the assisted living philosophy and a written statement of the administrator's understanding of the philosophy; and
 - (g) Name of the management company.
- (3) Identification. Every facility shall have distinct identification or name and shall notify the Division prior to changing such identification.
- (4) Descriptive Titles. An assisted living facility licensed by the Division shall neither assume a descriptive title nor be held under any descriptive title other than that which is permitted within the scope of its license.
- (5) Reporting of Changes. Each assisted living facility shall promptly report to the Division, changes which would affect the current accuracy of Section (2) of this rule.
- (6) Submission of Plans
- (a) One set of building plans and specifications shall be submitted to the Oregon Health Division, Licensing Plans Review Program, for approval:
 - (A) Prior to construction of any new building;
 - (B) Prior to construction of any addition to an existing building;
 - (C) Prior to any remodeling, modification, or conversion of an existing building; or
 - (D) In support of any application for an initial license of a facility not previously licensed under this rule;
 - (b) Plans shall comply with the current edition of the State Fire and Life Safety Code.
 - (c) Plans shall be drawn to a scale of one-fourth inch or one-eighth inch to the foot and shall specify the date upon which construction, modification, or conversion is expected to be completed.
 - (d) Construction containing 4,000 square feet or more shall be prepared and bear the stamp of an Oregon licensed architect or engineer.
- (7) Required Fees
- (a) Each application for an assisted living facility license shall be accompanied by the required non-refundable fee.
 - (b) No fee shall be required of a government owned facility.

(8) License Issued

- (a) Upon receipt of an application and fee, the Division shall cause an investigation to be made. Initial action by the Division on the application shall begin within 30 days of receipt of application;
- (b) The Division shall issue a license to an applicant found to be in compliance with these rules. The license shall be in effect for two years from the date issued unless revoked or suspended.
- (c) No assisted living facility license is transferable or applicable to any location, facility, management agent or ownership other than that indicated on the application and license.
- (d) No assisted living facility shall be operated or maintained in combination with a nursing facility, hospital, residential care, congregate care or other type of retirement facility unless licensed, maintained and operated as a separate and distinct part.
- (e) The license shall be posted in public view in the facility and available for inspection at all times.
- (f) Each license shall be considered void immediately on suspension or revocation of the license, or if the operation is discontinued by voluntary action of the license holder, or if there is a change of ownership. The voided license shall be returned to the Division immediately.

(9) Renewal of License

- (a) A license is renewable upon submission of an application to the Division and the payment of the required non-refundable fee, except that no fee shall be required of a governmental owned facility.
- (b) Filing of an application for renewal before the date of expiration extends the effective date of expiration until the Division takes action upon such application.

411-056-0010 Responsibilities of Administration

- (1) The facility shall develop and conduct an ongoing quality improvement program that evaluates services, resident outcomes and resident satisfaction.
- (2) The facility shall develop and implement written policies and procedures approved by the Division that promote high quality services, health and safety for residents and incorporate the assisted living principles of individuality, independence, dignity, privacy, choice, and a home-like environment.
- (3) The facility shall ensure that all employees and residents have a tuberculin test in

compliance with Health Division Administrative Rules, Chapter 333, Division 019. Documentation of results shall be available for review by the Division.

- (4) The facility shall evaluate prospective employees consistent with OAR Chapter 411, Division 009, Criminal History Clearance.
- (5) Abuse and Reporting
 - (a) The facility shall not inflict, or tolerate to be inflicted, abuse of residents.
 - (b) All employees who have reasonable cause to believe a resident has suffered abuse are responsible for reporting to appropriate facility personnel, SDS, or the State Long Term Care Ombudsman Office. Upon receipt of an allegation of abuse the facility shall immediately conduct an investigation. The facility administrator shall notify the local SDS/AAA office of the incident unless the facility investigation reasonably concludes that abuse did not occur.
 - (A) A person who, in good faith, reports abuse shall have immunity from any civil or criminal liability with respect to the making, or content of a report. Immunity under this subsection does not protect a self-reporting facility from liability for the underlying conduct, if any, that is described in the report.
 - (B) No complainant, witness, resident or employee of a facility shall be subject to any retaliation. If the employee is the complainant, he or she shall not be dismissed or harassed for making a good faith report, or being interviewed about a complaint, or being a witness.
- (6) The facility shall identify methods of preventing and responding to incidents such as injury, loss of property and abuse.
- (7) The facility shall exercise reasonable precautions against any condition which could threaten the health, safety or welfare of residents.
- (8) The facility is responsible for the supervision, training and overall conduct of staff when acting within the scope of their employment duties.
- (9) The facility shall develop and implement effective methods of resolving resident complaints.
- (10) Resident Bill of Rights. The facility shall implement a residents' Bill of Rights. Each resident or resident's designated representative shall be given a copy of their rights and responsibilities. The Bill of Rights shall state that residents have the right:
 - (a) To be treated with dignity and respect;
 - (b) To be given informed choice and opportunity to select or refuse service and to accept responsibility for the consequences;

- (c) To exercise individual rights that do not infringe upon the rights or safety of others;
- (d) To be free from neglect, financial exploitation, verbal, mental, physical or sexual abuse;
- (e) To receive services in a manner that protects privacy and dignity;
- (f) To have access to his/her records;
- (g) To have medical and other records kept confidential except as otherwise provided by law;
- (h) To interact freely with others within their assisted living home and in the community;
- (i) To be free from physical restraints and inappropriate use of psychoactive medications;
- (j) To manage personal financial affairs unless legally restricted;
- (k) To have access to and participate in social activities;
- (l) To be encouraged and assisted to exercise rights as a citizen.
- (m) To voice grievances, be informed of grievance procedures, and suggest changes in policies and services to either staff or outside representatives without fear of retaliation;
- (n) To have a safe and homelike environment;
- (o) To be free of discrimination in regard to race, color, national origin, gender, sexual orientation or religion; and
- (p) To have proper notification if requested to move out of the facility, and to be required to move out only for reasons stated in OAR 411-056-020, Involuntary Move-out Criteria, and have the opportunity for an informal conference and hearing.

411-056-0015 Range of Services

- (1) Initial Screening
 - (a) The facility shall determine whether a potential resident meets the facility's admission requirements.
 - (b) Prior to the resident moving in, an appropriate staff person shall conduct an initial screening to determine the prospective resident's service needs and preferences. The screening shall determine the ability of the facility to meet those needs and preferences considering the needs of the other residents and the facility's overall

service capability.

- (c) Based on the initial screening, an initial service plan shall be developed before the resident moves into the assisted living facility. The initial service plan shall be reviewed within 30 days of move-in to ensure the plan accurately reflects the resident's needs and preferences.

(2) Service Plan and Assessment

- (a) A service plan shall be developed and followed for each resident consistent with that person's unique physical, psycho-social, and health care needs with recognition of his/her capabilities and preferences.
- (b) The plan shall include a written description of: who will provide the services, what, when, how, and how often the services will be provided, and if applicable, the desired outcome. Each resident shall actively participate in the development of the service plan to the extent of his/her ability to do so. The resident or legal representative shall be offered a copy of the agreed upon service plan.
- (c) The plan shall reflect assessed needs and resident decisions (including resident's level of involvement), support principles of dignity, privacy, choice, individuality, independence, and a home-like environment; and identify others who will participate in the delivery of services.
- (d) A service plan shall be developed by a service planning team. The service planning team shall consist of the resident or legal representative and two or more of the following persons:
- (A) SDS/AAA case manager, if applicable;
 - (B) Facility administrator or designee; and
 - (C) A licensed nurse if the resident will be, or is, receiving nursing services.
- (e) In addition, the service planning team may include any or all of the following persons as appropriate, or as requested by the resident or his/her legal representative:
- (A) Facility personnel such as direct care givers, activity director, food preparer, etc.;
 - (B) Resident's physician or other health practitioner; and
 - (C) Other persons as requested by the resident or his/her legal representative.
- (f) The service planning team, shall:
- (A) Conduct an assessment of the resident's needs;
 - (B) Plan responsive services;

- (C) Implement services; and
 - (D) Periodically evaluate results of the plan.
- (g) The service plan shall be reviewed and updated quarterly by the service planning team and the resident, or more often, if the resident's needs change requiring service plan modification. The service plan shall be updated based on a current assessment of the resident.
 - (h) The service plan shall be readily available and followed by all staff.
 - (i) Managed risk. The service plan shall include agreed upon actions if a managed risk plan is developed.
 - (j) The facility shall identify the need for and develop a managed risk plan following the facility's established guidelines and procedures. A managed risk plan shall include:
 - (A) An explanation of the cause(s) of concern;
 - (B) The possible negative consequences to the resident and/or others;
 - (C) A description of resident preference(s);
 - (D) Possible alternatives/interventions to minimize the potential risks associated with the resident's current preference/action;
 - (E) A description of the services the facility will provide to accommodate the resident's choice or minimize the potential risk; and
 - (F) The final agreement, if any, reached by all involved parties.
 - (k) The facility shall involve the resident, the resident's designated representative and others as indicated, to develop, implement and review the managed risk plan. The resident's preferences shall take precedence over those of a family member(s). A managed risk plan shall not be entered into or continued with or on behalf of a resident who is unable to recognize the consequences of his/her behavior or choices.
 - (l) The managed risk plan shall be reviewed at least quarterly.
- (3) Services
- (a) The assisted living facility shall provide the following:
 - (A) Three nutritional meals daily with snacks available seven days a week, in accordance with the recommended dietary allowances found in the USDA Food Guide Pyramid, including seasonal fresh fruit and fresh vegetables;

- (B) Modified Special diets which are appropriate to residents' needs and choices;
 - (C) Menus prepared at least one week in advance, and made available to all residents. Meal substitutions may be made in compliance with this subsection. The facility shall encourage residents' involvement in developing menus.
 - (D) Personal and other laundry services;
 - (E) A program of social and recreational activities that is based upon individual and group interests and creates opportunities for active participation in the community at large;
 - (F) Services to assist the resident in performing all activities of daily living, on a 24-hour basis, including:
 - (i) Assistance with mobility, including one-person transfers;
 - (ii) Assistance with bathing/personal hygiene;
 - (iii) Assistance with dressing/grooming;
 - (iv) Assistance with eating;
 - (v) Assistance with bowel and bladder management, including incontinency management;
 - (vi) Intermittent cuing, redirecting and environmental cues for cognitively impaired residents;
 - (vii) Services for residents who exhibit behavioral symptoms that may benefit from intermittent intervention, supervision, and staff support;
 - (G) Household services essential for the health and comfort of the resident that are based upon the resident's needs and preferences. (e.g., floor cleaning; dusting, bed making, etc.);
- (b) The assisted living facility shall provide or arrange for the following:
- (A) Transportation for medical and social purposes;
 - (B) Ancillary services for medically related care (e.g. physician, pharmacist, therapy, podiatry), barber/beauty services, social/recreational opportunities, hospice, home health, and other services necessary to support the resident;
 - (C) Maintenance of a personal fund account for residents that documents deposits and withdrawals;
- (c) The facility shall provide health services which include:

- (A) Accessing first payor benefits to provide health care for residents who are eligible for those benefits. When benefits are no longer available or if the resident is not eligible for benefits, the facility shall provide or coordinate the required services for residents whose health status is stable and predictable.
 - (B) An Oregon-licensed registered nurse, either on staff or on contract who provides;
 - (i) Health care assessment and periodic monitoring of residents as appropriate;
 - (ii) Assignment of basic tasks of nursing and delegation of special tasks of nursing in accordance with the Oregon State Board of Nursing Administrative Rules, Chapter 851, Division 047;
 - (C) Providing intermittent nursing services for a resident whose medical needs are stable and predictable. The facility shall assist in the coordination of nursing care such as home health, when a resident's medical condition is complex, unstable, or unpredictable, and such care can be managed in the facility.
 - (D) Oversight and monitoring of resident's health status;
 - (E) Health care teaching and counseling;
 - (F) Interaction with other health care professionals on behalf of the resident as needed;
 - (G) Coordinating the provision of health services with outside service providers such as hospice, home health, physicians' offices etc.;
 - (H) Systems which respond to the health and medical care needs of residents on a 24-hour basis.
 - (I) Immediate notification to medical, emergency, or police personnel when a restraint is applied because a resident's actions present an imminent danger to self or others.
- (4) Medications and Treatments
- (a) Medication/Treatment Administration
 - (A) The facility shall have safe medication and treatment administration systems in place that are approved by a pharmacist consultant, registered nurse, or physician. The administrator is responsible for ensuring adequate professional oversight of the medication and treatment administration system.
 - (B) Written, signed physician or other legally recognized practitioner orders shall be documented in the resident's facility record for all medications and treatments

which the facility is responsible to administer. Medication or treatment changes shall not be made without a physician's or other legally recognized practitioner's order.

- (C) All medications administered by the facility to a resident shall be reviewed at least every ninety days by the prescriber, registered pharmacist, or registered nurse.
- (D) Medication and treatment orders shall be carried out as prescribed. The resident or the person legally authorized to make health care decisions for the resident has the right to consent to, or refuse medications and treatments. The physician/practitioner shall be notified if a resident refuses consent to an order. Subsequent refusals to consent to an order shall be reported as required by the physician/practitioner.
- (E) An accurate medication record for each resident shall be kept of all medications, including over-the-counter medications, administered by the facility to that resident. The record shall include:
 - (i) Name of medication, reason for use, dosage, route and date/time given;
 - (ii) Name of the primary care or prescribing physician/nurse practitioner and telephone number;
 - (iii) Current month, day and year;
 - (iv) Allergies and sensitivities, if any;
 - (v) Resident specific parameters and instructions for p.r.n. (as needed) medications;
 - (vi) Documentation of treatments with resident specific parameters;
 - (vii) Initials of the person administering the medication and treatment at the time of administration; and
 - (viii) Review date and name of reviewer.
- (F) The facility shall maintain legible signatures of staff who administer medications and treatments, either on the medication administration record or on a separate signature page;
- (G) Residents may keep and use over-the-counter medications in their unit without a written order unless otherwise contraindicated by a physician or other legally recognized practitioner's written orders;
- (H) If the facility administers or assists a resident with his/her medication, all medication obtained through a pharmacy shall be clearly labeled with the

pharmacist's label in the original container in accordance with the facility's established medication delivery system.

- (I) Over-the-counter medication or samples of medications shall have the original manufacturer's label(s) if the facility administers or assists a resident with his/her medication.
 - (J) The facility shall not require residents to purchase prescriptions from a pharmacy which contracts with the facility. The facility shall comply with ORS 443.437, Residential Facilities and Homes, regarding prescription and non-prescription medications and supplies.
 - (K) The facility shall have a system approved by a pharmacist consultant, registered nurse, or physician, for tracking controlled substances and for disposal of all unused, outdated or discontinued medications administered by the facility.
 - (L) All medications administered by the facility shall be stored in a locked container(s) in a secured environment such as a medication room or medication cart.
 - (M) The facility shall obtain and place a written signed order in the resident's record for any medications administered by the facility. Order changes obtained by telephone must be followed-up with written, signed orders.
- (b) Psychoactive Medication
- (A) The facility shall not request psychoactive medication to treat a resident's behavioral symptoms without a consultation from a physician, nurse practitioner, registered nurse or mental health professional. Facility administered psychoactive medication(s) shall be used only when required to treat a resident's medical symptoms or to maximize a resident's functioning.
 - (B) Prior to administering any psychoactive medication(s) to treat a resident's behavior, all caregivers providing care for the resident shall know the specific reasons for the use of the psychoactive medication for that resident, the common side effects and when to contact a health professional regarding side effects. P.R.N. medications that are given to treat a resident's behavior shall have written, specific parameters. These medication(s) may be used only after documented, non-pharmacological interventions have been tried ineffective results. All caregivers shall have knowledge of non-pharmacological interventions.
 - (C) Psychoactive medications shall not be given to discipline a resident, or for the convenience of the facility. Psychoactive medications may be used only pursuant to a prescription that specifies the circumstances, dosage and duration of use.
- (c) Self - Medication

- (A) Residents must have a physician's or other legally recognized practitioner's written order of approval for self-administration of prescription medications. The resident shall be encouraged to have his/her medications reviewed by the prescriber, nurse practitioner, registered nurse or pharmacist at least every 90 days;
- (B) Residents able to administer their own medication regimen may keep prescription medications in their unit; and
- (C) If more than one resident resides in the unit, an assessment will be made of each person and his/her ability to safely have medications in the unit. If safety is a factor, the medications shall be kept in a locked container in the unit;

411-056-0018 Direct Care Staff

- (1) The facility shall have qualified staff sufficient in number, to meet the 24-hour scheduled and unscheduled needs of each resident, and respond in emergency situations.
- (2) Staff or volunteers under 18 years of age shall not assist with medication administration or delegated nursing tasks. Staff or volunteers under the age of 18 must be supervised when providing bathing, toileting or transferring services.
- (3) A staff member on each shift shall be trained in the use of the Heimlich Maneuver, CPR and First Aid.
- (4) Staff shall have sufficient communication and language skills to enable them to perform their duties and interact effectively with residents and other staff.
- (5) Prior to providing care, staff shall receive documented orientation and training as approved by the Division. Training topics shall include:
 - (a) Principles of assisted living;
 - (b) Changes associated with aging processes including dementia;
 - (c) Resident's rights, including confidentiality;
 - (d) How to perform direct ADL care;
 - (e) Location of resident service plans and how to implement;
 - (f) Fire safety/emergency procedures;
 - (g) Responding to behavior issues;
 - (h) Standard precautions for infection control;

- (i) Food preparation, service and storage, if applicable; and
 - (j) Observation/reporting skills.
- (6) Staff shall comply with OAR Chapter 411, Division 009, Criminal History Clearance and OAR Chapter 333, Division 019, Health Division, Tuberculosis testing.

411-056-0020 Involuntary Move-Out Criteria

The Division encourages facilities to support a resident's choice to remain in his or her living environment while recognizing that some residents may no longer be appropriate for the assisted living setting due to safety and medical limitations.

- (1) A resident may, but is not required to be, asked to leave under the following circumstances:
 - (a) Residents shall be given 30 days written notice when they are requested to move-out for the following reasons:
 - (A) The resident's needs exceed the level of ADL services the facility provides. There shall be documentation of the facility's efforts to provide or arrange for the required services. The minimum required services identified in OAR 411-056-0015(3) shall be provided before a resident can be asked to move-out for this reason;
 - (B) The resident exhibits behavior or actions that repeatedly and substantially interferes with the rights or well being of other residents and the facility has tried prudent and reasonable interventions. There shall be documentation of the interventions attempted;
 - (C) The resident, due to severe cognitive decline, is not able to respond to verbal instructions, recognize danger, make basic care decisions, express need or summon assistance;
 - (D) The resident has a medical condition that is complex, unstable or unpredictable and treatment cannot be appropriately developed and implemented in the assisted living environment. There shall be documentation of the facility's efforts to obtain appropriate care for the resident; or
 - (E) Non-payment of charges.
 - (b) The resident may be asked to move-out with less than 30 days, but not less than 14 days written notice for the following reasons:
 - (A) The resident exhibits behavior that is an immediate danger to self or others;

- (B) The resident has had a sudden change in condition that requires medical or psychiatric treatment outside the facility and at the time the resident is to be discharged from that setting to move back into the facility, appropriate facility staff have re-evaluated the resident's needs and have determined the resident's needs exceed the facility's level of service. If the resident appeals the notification to move-out, the facility shall not rent the resident's unit pending completion of the appeals process;
 - (C) The facility is unable to accomplish resident evacuation in accordance with OAR 411-056-0035; or
 - (D) The resident requires 24 hour, seven day a week nursing supervision.
- (c) A resident or his/her legal representative may be given less than 14 days notice with written consent from the Division. All appeal rights shall remain intact.
 - (d) A resident or his/her legal representative shall be given at least 30 days notice if a facility has had its license revoked, not renewed, or voluntarily surrendered.
 - (e) A resident or his/her legal representative may terminate residency of a resident without notice due to abuse or conditions of imminent danger to life, health or safety, as substantiated by an SDS/AAA office, or the Division.
- (2) The written move-out notice shall be completed on a Division approved form. The form shall be filled out in its entirety and a copy of the notice shall be sent by certified mail or delivered in person to the resident, the resident's legal representative, or any person designated by the resident, guardian, or conservator and if applicable, the case manager. Where a person lacks capacity and there is no legal representative, a copy of the notice to move-out shall be faxed or sent next-day delivery to the State Long Term Care Ombudsman, who may request an informal conference for the resident.
- (3) Residents who are given 14 day or less, notification to move-out and who object to the requirement to move shall be given the opportunity of an informal conference if requested within five working days after receiving the notification. If notification is given under Section (1), Subsection (a) of this rule, the resident has ten days to object after receiving notification. When a resident or designee requests an informal conference, the Division shall be notified by the facility.
 - (4) The Division shall hold an informal conference as promptly as possible, but no later than seven working days after the request is received. Participants shall include the resident and others as requested by the resident. The purpose of the informal conference is to resolve the matter without a formal hearing. If a resolution is reached at the informal conference, no formal hearing will be held. If a resolution is not reached at the informal conference, the resident or resident's representative may request a formal hearing. The administrative hearing will be held within seven days from the request if the requirement to move has been given for the protection and welfare of the resident or other residents.
 - (5) The resident shall have the right to a formal administrative hearing prior to an involuntary

move-out.

- (6) Temporary absence for medical treatment is not considered a move-out.
- (7) Intra-facility move policy shall be included in the facility's disclosure statement. In the case of a facility requested move, the facility shall pay all associated costs with the move. Residents shall not be relocated from one unit to another for the convenience of the facility.

411-056-0030 Organization of Business

(1) Administrative Standards

- (a) The licensee shall be responsible for the operation of the facility.
- (b) Each licensed assisted living facility shall employ a full-time administrator.
- (c) The administrator is designated by the licensee as the person responsible for the daily operation of the facility and for the daily care provided in the facility.
- (d) The administrator shall appoint a staff member as designee to oversee the operation of the facility in the administrator's absence. The administrator or designee shall be in charge on site, at all times and shall ensure there are sufficient, qualified staff and the care, health and safety needs of the residents are met at all times.
- (e) The administrator shall maintain and post in public view the facility staffing plan and the name of the administrator or designee in charge shall be posted by shift.

(2) Administrator Qualifications

- (a) Facility administrators hired, or transferred between facilities, on or after April 1, 1999, shall meet the following requirements:
 - (A) Be at least 21 years of age;
 - (B) Possess a high school diploma or equivalent;
 - (C) Have two years successful experience providing care to persons in a community based or long term care setting or have a minimum of two years education in a health related field, or a combination thereof;
 - (D) Complete 40 hours of Division-approved training prior to operating an assisted living facility;
 - (E) Have 20 hours of documented Division-approved continuing education credits each year. The 40-hour Division-approved training fulfills the 20-hour continuing education requirement for the first year; and

(F) Comply with OAR Chapter 411, Division 009, Criminal History Clearance and OAR Chapter 333, Division 019, Health Division, Tuberculosis testing.

- (b) The Division shall be notified within five days of an administrator's departure or employment. A new administrator shall receive or be enrolled in a 40-hour Division approved Administrator Training Course prior to assuming the responsibilities of administrator. An administrator enrolled in an approved training course shall complete the course within 60 days of hire. Until training has successfully been completed, a qualified person who has completed the 40 hour course shall provide on-site supervision.

(3) Administrator Training Course Standards

- (a) The Division shall approve, in writing, the training curriculum for the 40-hour Administrator Training. The curriculum shall be re-evaluated by the Division at periodic intervals.
- (b) Individuals, companies or organizations providing the Administrator Training Course shall be approved by the Division. The Division may withdraw approval under the following conditions;
- (A) Failure to follow the Division approved curriculum;
 - (B) The trainer demonstrates lack of competency in training;
 - (C) There is insufficient frequency of training to meet the need; or
 - (D) Facilities owned or operated by the training entity have a pattern of substantial non-compliance with these rules.
- (c) Approved training shall be open and available to all applicants and shall not be used to orient trainees to a specific company's management or operating procedures.

(4) Financial Management

The assisted living facility shall have written policies, procedures, and accounting records for handling residents' personal incidental funds, which are managed in the resident's own best interest.

- (a) The resident may manage his/her personal financial resources, or may authorize another person or the assisted living facility to manage personal incidental funds.
- (b) Records shall include a statement as to whether or not the facility will handle the resident's money, if requested by the resident .
- (c) Records shall include the Resident Account Record (SDS 713) or other comparable expenditure form if the facility manages or handles a resident's money. The resident

account record shall show in detail with supporting documentation all monies received on behalf of the resident and the disposition of all funds received. Persons shopping for residents shall provide a list showing description and price of items purchased, along with payment receipts for these items.

- (d) Funds containing more than \$150, shall be maintained in the resident's own interest-bearing account or in an interest bearing account with a system that credits the appropriate interest specifically to each resident.
 - (e) Upon the death of a Medicaid resident, with no surviving spouse, any personal incidental funds held by the facility for the resident shall be forwarded to SDSD, Estate Administration Unit, P.O. Box 14021, Salem, OR 97309.
- (5) Disclosure - Residency Agreement
- (a) Prior to a resident moving-in, the facility shall provide a residency agreement and disclosure statement to each potential resident or his/her designated representative. The residency agreement and disclosure statement must be approved by the Division prior to distribution and shall include the following:
 - (A) Terms of occupancy;
 - (B) Payment provisions, including the following:
 - (i) Basic rental rate, and what it includes;
 - (ii) Additional services costs;
 - (iii) Billing method, payment system and due dates;
 - (iv) Deposits/fees, if applicable;
 - (C) Policy for rate changes including:
 - (i) Thirty days prior written notice of any facility-wide increases, additions or changes;
 - (ii) Immediate written notice at the time the facility determines a resident's service rates will increase due to increased service provision as negotiated in a service plan;
 - (D) Refund/proration conditions;
 - (E) A description of the scope of services available according to OAR 411-056-0015;
 - (F) A description of the service planning process and the relationship between the service plan and cost of services;

- (G) Additional available services;
 - (H) The philosophy of how health care and ADL services are provided to the resident;
 - (I) Resident rights and responsibilities;
 - (J) The facility system for packaging medications and the resident's right to choose a pharmacy;
 - (K) Criteria, actions, circumstances or conditions which may result in a move-out notification or intra-facility move and resident's rights pertaining to notification of move-out;
 - (L) Notice that the Division has the authority to examine resident's records as part of the evaluation of the facility; and
 - (M) Staffing plan.
- (b) The facility shall not include any provision in a residency agreement or disclosure statement that is in conflict with these rules and shall not ask or require a resident to waive any of the resident's rights or the facility's liability for negligence.
 - (c) The facility shall retain a copy of the signed and dated residency agreement and provide copies to the resident or to their designated representative; and
 - (d) The facility shall give 30 days prior written notice of any additions or changes to the residency agreement.

411-056-0035 Fire and Life Safety

- (1) **Building and Fire Codes.** Each assisted living facility shall meet the requirements of the Oregon Structural Specialty Code (OSSC), and the Oregon Uniform Fire Code (OUFC) in effect at the time of original licensure and as required by building and fire code agencies having jurisdiction. When a change in use and building code occupancy classification occurs, licensure approval shall be contingent on meeting the OSSC and minimum standards of ADA in effect at the time of such change.
- (2) **Emergency Procedure and Disaster Plan.** A written emergency procedure and disaster plan for meeting all emergencies and disasters shall be approved by the State Fire Marshal or authorized representative. The plan shall be immediately available to the administrator and employees. The plan shall include:
 - (a) Emergency instructions for employees in the event of fire, explosion, missing person, accident, or other emergency;
 - (b) The telephone numbers of the local fire departments, police departments, the

administrator, the administrator's designee, and other persons to be contacted in emergencies; and

- (c) Instructions for the evacuation of residents and employees in the event of a fire, explosion, or other emergency.
- (3) **Combustible and Hazardous Materials.** Flammable and combustible liquids or hazardous materials shall be safely and properly stored in original, properly labeled containers in areas inaccessible to residents in accordance with the OUF.C.
 - (4) **Safety Evacuation Capability**
 - (a) The evacuation capability of the residents and staff is a function of both the ability of the residents to evacuate and the assistance provided by the staff. Facilities classified as impractical or slow shall meet one of the following evacuation levels:
 - (A) **SR-1 Impractical.** A group, even with staff assistance, that cannot reliably move to a point of safety in a timely manner, and evacuation drill times are in excess of 13 minutes;
 - (B) **SR-2 Slow.** A group that can move to a point of safety in a timely manner with some assistance and have evacuation drill times over three minutes, but not in excess of 13 minutes.
 - (b) All two story assisted living facilities with approved plans or constructed on or after April 1, 1999, shall be constructed to meet SR-1 standards, or if an SR-2 classification is used, shall include a minimum of one 2 hour area separation wall, constructed to standards as defined in the OSSC.
 - (c) All existing facilities shall be subject to review and may be reclassified into one of these two classification groups. Waivers shall be given only with the approval of the Fire Marshal Agency having jurisdiction.
 - (5) **Approved Documentation of Evacuation Capability.** The assisted living facility shall document, on State Fire Marshal forms, the evacuation capability of the residents as specified in the OUF.C.
 - (6) **Fire Drills.** A minimum of one unannounced fire drill shall be conducted and recorded every other month. Each month a fire drill is conducted, the time (day, evening and night shifts) and location of the drill shall vary. Fire and life safety instruction to staff will be provided on alternate months. The facility or local Fire Marshal may develop alternative fire drill plans in consultation with the State Fire Marshal or his designee. Any such plan shall be submitted to the Division for approval.
 - (7) **Evacuation Assistance.** Staff shall provide fire evacuation assistance to residents from the building to a designated meeting area outside the building through a horizontal exit (2-hour minimum fire wall) or other points of safety approved by the State Fire Marshal or his designee.

- (8) **Inability to Evacuate.** When the facility is unable to meet the applicable evacuation level, the facility shall make an immediate effort to make changes to ensure the evacuation standard is met. Changes shall include, but are not limited to, increasing staff levels, changing staff assignments, requesting intra-facility move of resident(s) and arranging for special equipment. The facility shall document efforts to accomplish evacuation. If the facility cannot meet the applicable evacuation level, the facility shall prepare to move out the resident(s) in accordance with OAR 411-056-0020.
- (9) **Alternative Exit Routes.** Alternate exit routes shall be used during fire drills to react to varying potential fire origin points.
- (10) **Fire Alarms or Smoke Detectors.** Fire alarms, smoke detectors, or other approved signal devices shall be set off during each fire drill. Fire detection and protection equipment, including visual signals with alarms for hearing-impaired residents, shall be inspected and maintained in accordance with the requirements of the State Fire Marshal or authorized representative.
- (11) **Fire Drill Records.** A written fire drill record shall be kept to include the date and time of day, location of simulated fire origin, the escape route used, comments relating to residents who refused or were unable to participate in the drills, whether the alarm system was operative at the time of the drill and evacuation time period needed. Records shall be maintained for a minimum of 24 months.
- (12) **Safety Program.** A safety program shall be developed and implemented to avoid hazards to residents such as dangerous substances, sharp objects, unprotected electrical outlets, slippery floors or stairs, exposed heating devices, broken glass, water temperatures and fire prevention.
- (13) **Training for Residents.** Residents shall be instructed about the facility's safety procedures.
 - (a) Each resident shall be instructed within 24 hours of admission and reinstructed annually in general safety procedures, evacuation methods, responsibility during fire drills, designated meeting places outside the building or within the fire safe area in the event of an actual fire, and smoking safety procedures if residents smoke in the building. This requirement does not apply to a resident whose mental capability does not allow for following such instructions.
 - (b) A written record of fire safety training, including content of the training sessions and the residents attending, shall be kept.
 - (c) All residents shall be encouraged to actively participate in the bi-monthly fire drills. All participating residents shall evacuate in accordance with subsection (7) of this rule.
- (14) **Unobstructed Egress.** Stairways, halls, doorways, passageways and exits from rooms and from the building shall be unobstructed.

- (15) **Smoking.** A resident's ability to smoke safely shall be evaluated and addressed in the service plan.
- (a) An assisted living facility can designate itself as non-smoking;
 - (b) If a facility designates itself non-smoking, this information shall be disclosed in the residency agreement;
 - (c) The rights of non-smoking residents shall be given priority in settling smoking disputes between residents;
 - (d) If there is a designated smoking area within the facility common areas, it shall be designed to keep other common areas smoke free; and
 - (e) The facility shall provide 30-days written notice to all residents if a facility adopts a non-smoking policy and shall include accommodations for residents who smoked prior to the change.
- (16) **First-Aid Supplies.** First-aid supplies shall be provided, properly labeled and readily accessible.
- (17) **Fire extinguisher(s).** The provider shall provide and maintain one or more 2A10B fire extinguishers on each floor in accordance with the OUFC.

411-056-0040 Facility Standards

Facilities which have building plans approved, on or after April 1, 1999, must comply with the Oregon Structural Specialty Code (OSSC), Oregon Uniform Fire Code (OUFC), Title III of the Americans with Disabilities Act (ADA), and Fair Housing Act, Fair Housing Design Guidelines (FHA) where applicable, and the facility standards set forth in these rules. Facilities which are licensed or have had their construction plans approved by the Division are exempt from any new physical plan requirements before the effective date of these rules. All remodeling or modifications made to a facility on or after April 1, 1999 shall be subject to requirements in place at that time.

- (1) **Physical Environment Generally**
- (a) All facilities shall meet adaptable and accessible requirements of the OSSC, ADA, and FHA, where applicable, in effect at the time of plan approval.
 - (b) All interior and exterior materials and surfaces (e.g., floors, walls, roofs, ceilings, windows, and furniture) and all equipment necessary for the health, safety and comfort of the resident shall be kept clean and in good repair.
 - (c) Measures shall be taken to prevent the entry of rodents, flies, mosquitos and other insects.

- (d) The facility grounds shall be kept orderly and free of litter and refuse.
 - (e) All exterior pathways and/or accesses to the facility's common use areas and entrance/exit ways shall be of hard, smooth material, accessible, and be maintained in good repair.
 - (f) An accessible outdoor recreation area is required which shall be available to all residents and have lighting equal to a minimum of five foot candles.
- (2) Storage. The facility shall include sufficient storage for the following:
- (a) Locked storage for all poisons, chemicals, rodenticide, and other toxic materials. All materials shall be properly labeled;
 - (b) Locked storage for any flammable and combustible materials. Materials shall be properly labeled and stored in their original containers;
 - (c) All maintenance equipment used and stored at the facility, including yard maintenance tools; and
 - (d) Garbage stored in covered refuse containers.
- (3) General Building Interior
- (a) Elevators. Facilities with residents on more than one floor, with approved building plans on or after April 1, 1999, shall provide at least one elevator that shall meet Oregon Elevator Specialty Code (OESC) requirements.
 - (b) Corridors. Facilities with building plans approved, on or after April 1, 1999 must comply with the corridor standards set forth in these rules.
 - (A) Resident-use areas and units shall be accessible through temperature controlled common corridors with a minimum width of 48 inches. Resident-use corridors exceeding 20 feet in length to an exit or common area, shall have a minimum width of 72 inches.
 - (B) Corridors shall not exceed 150 feet in length from any resident unit to a seating or other common area.
 - (C) Handrails shall be installed at one or both sides of resident use corridors.
 - (c) Floors
 - (A) Hard surface floors and base shall be free from cracks and breaks.
 - (B) Carpeting and other floor materials shall be constructed and installed to minimize resistance for passage of wheelchairs and other ambulation aids. Thresholds and floor junctures shall also be designed and installed for passage of

wheelchairs and to prevent a tripping hazard.

- (d) **Finishes.** Walls and ceilings shall be washable in kitchen, laundry and bathing areas in facilities with building plans approved on or after April 1, 1999. Kitchen walls shall be finished smooth per Oregon Health Division Food Sanitation Rules, OAR 333-156-0080.
- (e) **Doors**
 - (A) In facilities with building plans approved on or after April 1, 1999, all doors to resident units, bathrooms and other common use areas shall provide a minimum clear opening of 32 inches (36-inch doors recommended);
 - (B) Lever-type or other OSSC/ADA approved hardware shall be provided on all doors used by residents; and
 - (C) Exit doors shall not include locks which prevent evacuation except as approved by the Fire Marshal and building codes agencies having jurisdiction. Such locks shall not be installed except for purposes of resident safety and with written approval by the Division.
- (f) The interior of the facility shall be free from unpleasant odors.

411-056-0045 Resident Units and Common Use Areas

- (1) All resident units shall be comprised of individual adaptable and accessible apartments with a lockable door, private bathroom and kitchenette facilities conforming to the requirement of the OSSC, FHA and the facility standards set forth in these rules. Designers shall emphasize a residential appearance while retaining the features required of such a facility to support special resident needs as outlined in this rule.
- (2) **Unit Dimensions.** New construction units shall have a minimum of 220 net square feet not including the bathroom. Units in pre-existing structures being remodeled shall have a minimum of 160 square feet not including the bathroom. Each unit shall have a bathroom as required in section (5), subsection (a) through (d) of this rule.
- (3) **Windows**
 - (a) All units shall have an escape window that opens directly onto a public street, public alley, yard or exit court. This window section shall be operable from the inside to provide a full clear opening without the use of separate tools and shall have a minimum net clear open area of 5.7 square feet, a minimum net clear opening height of 24 inches, a minimum net clear open width dimension of 20 inches and shall not be below grade.
 - (b) Each resident's living room and bedroom shall have exterior windows which have an area at least one-tenth of the floor area of the room. One window shall be at least 3'-

6" x 5'-0" in size and have a maximum sill height of 36". Operable units shall be designed to prevent accidental fall when sill heights are lower than 36".

- (c) Bedroom windows shall be equipped with curtains or blinds for privacy and control of sunlight.

(4) Doors

- (a) Each unit shall have an entry door which is self-closing, does not swing into the exit corridor, and is equipped with lever handles. A locking device shall be included which is released with action of the inside lever. The lock for the entry door shall be individually keyed, master keyed, and a key supplied to the resident.
- (b) The unit exit door shall open to an indoor, temperature controlled, common area or common corridor.

(5) Bathroom

- (a) The unit bathroom shall be a separate room with a toilet, sink, roll-in shower, have at least one towel bar (36" in height), one toilet paper holder, one accessible mirror and storage for toiletry items. The door to the bathroom shall open outward or slide into the wall.
- (b) The unit bathroom shall have unobstructed floor space of sufficient size to inscribe a circle with a diameter of not less than 60 inches or a "T" turn conforming to the requirements of the OSSC and ADA, for maneuverability by residents using wheelchairs or other mobility aids. The "circle" or "T" may infringe in the space of the roll-in shower stall by a maximum of 12 inches.
- (c) Wall construction shall have proper and appropriately placed blocking near toilets and in showers to allow installation of grab bars.
- (d) Roll-in shower stalls shall meet OSSC and ADA requirements except as noted in this subsection. The minimum number of resident unit bathroom showers required by OSSC shall have a clear inside dimension of 36 inches deep by 60 inches long. All other resident unit showers shall have a minimum nominal dimension of 36 inches deep by 48 inches long. A folding seat is not required. Showers shall have non-slip floor surfaces in front of roll-in showers, a hand-held shower head, cleanable shower curtains, and appropriate grab bar. In facilities with plans approved on or after April 1, 1999, ramps shall not be allowed in front of roll-in showers.
- (e) Water closets and lavatories shall meet OSSC and ADA requirements to be fully accessible unless otherwise noted in this subsection. Water closets shall meet the minimum number required to be accessible by the OSSC unless otherwise noted in this subsection. The lavatory may have readily removable cabinets underneath or be readily adaptable to meet the OSSC and ADA requirements for a forward approach by a wheelchair. Grab bars for the water closet may be omitted provided all structural reinforcements for grab bar installation are provided in the appropriate locations in

adjoining walls.

- (6) **Kitchens.** Each unit shall have a kitchen area equipped with a sink, refrigerator, a cooking appliance that can be removed or disconnected, adequate space for food preparation, and storage space for utensils and supplies. In facilities with plans approved on or after April 1, 1999, counter heights shall be 34 inches; and the sink, refrigerator and cooking appliance shall meet OSSC and the ADA reach and clear floor space requirements for wheelchairs. The sink may have readily removable cabinets underneath or be readily adaptable to meet the OSSC and ADA requirements for a forward approach by a wheelchair. Fifty percent of the shelving shall be within the reach ranges per the OSSC and ADA.
- (7) **Resident Storage Space.** Each unit shall provide usable space totaling at least 100 cubic feet for resident clothing and belongings and include one clothes closet with a minimum of 4 linear feet of hanging space. The rod shall be adjustable for height or fixed at no higher than 48 inches and no lower than 36 inches for accessibility. In calculating usable space, closet height shall not exceed 8 feet and a depth of 2 feet. Kitchen cabinets shall not be included.
- (8) **Common Use Areas**
 - (a) **Bathing Room**
 - (A) There shall be a special bathing room with a tub with whirlpool action, accessible by side transfer, without the use of mechanical aids and designed for staff assistance.
 - (B) The room shall have individual heat control and be equipped with an exhaust to the outside.
 - (C) There shall be direct access to a toilet and sink in the same room or in an adjacent room.
 - (D) There shall be a non-slip floor surface required in facilities with plans approved on or after April 1, 1999.
 - (b) **Public Restrooms**
 - (A) There shall be accessible public restrooms for visitor, staff and resident use, convenient to dining and recreation areas.
 - (B) The room shall contain a toilet, sink, waste containers, and a hand drying means that cannot be reused.
 - (c) **Dining Room**
 - (A) The building shall have a dining area with the capacity to seat 100% of the residents.

- (B) The dining room(s) shall provide 22 sq. ft. per resident for seating, exclusive of service carts and other equipment or items that take up space in the dining room. This rule is exclusive of any separate private dining room(s).
- (d) **Reception Area.** A reception area shall be visible and accessible to residents and visitors when entering the doors of the main entrance to the facility.
- (e) **Social/Recreation Areas.** The building shall have common areas for social-recreational use totaling at least 15 sq. ft. per resident.
- (f) **Stove(s).** If a stove is provided in the activities/common area available for resident use, a keyed or remote switch or other safety device shall be provided to insure staff supervision.
- (g) **Resident Laundry Facilities.** Laundry facilities shall be operable at no additional cost with at least one washer and dryer accessible by residents using wheelchairs.
- (h) **Smoking Area.** If there is a designated smoking area, it shall be separate from other common areas, be indoors, and provided with mechanical exhaust.
- (i) **Mailbox.** Each resident/unit shall be provided a mailbox which meets OSSC and ADA reach and clear floor space requirements for wheelchairs. It shall also meet US Postal Service requirements.
- (9) **Support Service Areas**
- (a) **Medication Storage.** The facility shall provide a secured space for medication storage with access to a sink and cold storage in the same area. Space for necessary medical supplies and equipment shall be provided.
- (b) **Housekeeping/Sanitation.** The building shall have a secured janitor closet for storing supplies and equipment, with a floor or service sink.
- (c) **Laundry and Soiled Linen Storage.** For the purpose of this rule "soiled linens or soiled clothing" means linens or clothing soiled due to a resident's incontinence.
- (A) Laundry facilities may be located to allow for both resident and staff use when a time schedule for resident use is provided and equipment is of residential type. Laundry facilities shall be separate from food preparation and other resident use areas. When the primary laundry is not in the building or suitable for resident use, separate resident laundry facilities shall be provided.
- (B) On-site laundry facilities, used by staff for facility and resident laundry, shall have capacity for locked storage of chemicals and equipment.
- (C) There shall be a separate area or room and closed containers which ensure the separate storage and handling of soiled linens. Arrangement shall provide a one-

way flow of linens from the soiled area to the clean area and preclude potential for contamination of clean linens and clothing. Soiled linen and clothing shall be stored and processed separately from other linen and clothing.

- (D) The soiled linen room, or area, shall include a flushing rim clinical sink with rinsing device and a handwash sink or lavatory.
- (E) There shall be adequate space and equipment to handle laundry processing needs. When washing soiled linens, washers shall have a minimum rinse temperature of 140 degrees Fahrenheit (160 degrees recommended), unless a chemical disinfectant is used.
- (F) Covered or enclosed clean linen storage shall be provided which may be on shelves or carts. Clean linens may be stored in closets outside the laundry area.

(d) Kitchen and Food Storage

- (A) Food Sanitation. Assisted living facilities shall comply with Oregon Health Division Food Sanitation Rules Chapter 333, Divisions 150 through 175, for food handling and primary meal preparation areas.
- (B) Public toilet facilities required in this rule may also serve kitchen staff when conveniently available.
- (C) Dry storage space, not subject to freezing, shall store a minimum one week supply of staple foods.
- (D) There shall be refrigeration and freezer space at proper temperature to store a minimum two days supply of perishable foods.
- (E) Storage for all dishware and utensils used by residents shall meet Oregon Health Division Food Sanitation Rules.
- (F) Storage in the food preparation area for garbage shall be enclosed and separate from food storage.
- (G) Storage shall be available for cookbooks, diet planning information and records.

(10) Mechanical & Electrical Systems

- (a) Heating and Ventilation Systems. Heating and Ventilation systems shall conform to the Oregon Mechanical Specialty Code in effect at the time of facility construction.
 - (A) Temperature. For all areas occupied by residents, design temperature for construction shall be 75 degrees Fahrenheit. All existing facilities shall include heating systems capable of maintaining 68 degrees Fahrenheit in resident areas. Required minimum temperatures are no less than 68 degrees Fahrenheit during the day and 60 degrees Fahrenheit during sleeping hours. During times of

extreme summer heat, at the request of the resident, individual fans shall be provided or arranged for, when air conditioning is not provided.

- (B) Temperature Controls. Each unit shall have individual thermostatic heating controls.
 - (C) Exhaust Systems. All toilet, shower and smoking rooms shall be equipped with a mechanical exhaust fan or central exhaust system which discharges to the outside.
 - (D) Ventilation. Ventilation in each unit shall occur via an open window to the outside, or with a mechanical venting system capable of providing two air changes per hour with one-fifth of the air supply taken from the outside.
- (b) Plumbing Systems. Plumbing systems shall conform to the Oregon Plumbing Specialty Code in effect at the time of facility construction.
- (A) Plumbing. Hot water temperature in residents' units shall be maintained within a range of 110 - 120 degrees Fahrenheit.
 - (B) Hot water and laundry temperatures serving dietary areas shall equal 140 degrees Fahrenheit minimum and temperatures at dishwashers shall meet Oregon Health Division Food Sanitation Rules.
 - (C) Sprinkler System. Assisted living facilities with building plans approved on or after April 1, 1999, shall have a sprinkler system installed in accordance with the Oregon Uniform Fire Code;
 - (D) In facilities with building plans approved on or after April 1, 1999, an area drain and hot and cold water hose bibs shall be provided for sanitizing laundry carts, food carts and garbage cans.
- (c) Electrical Systems
- (A) Wiring Systems. All wiring systems shall meet the Oregon Electrical Specialty Code in effect at the date of installation and devices shall be properly wired and in good repair. When not fully grounded, circuits in resident areas may be protected by GFCI type receptacles or circuit breakers as an acceptable alternative.
 - (B) All electrical circuits shall be protected by circuit breakers or type S fuses and fuse holders of proper capacity. Electrical loads on circuits shall be limited in accordance with proper circuit capacity.
 - (C) Sufficient electrical outlets shall be provided to meet resident and staff needs without the use of extension cords or other special taps.
- (d) Lighting

- (A) Each unit shall have general illumination in the bath, kitchen, living space and sleeping area. The general lighting intensity in the unit for way finding shall be at least 20 foot candles measured from the floor.
 - (B) Lighting in the unit bathroom shall be at least 50 foot candles measured from the height of the basin.
 - (C) Task lighting at the unit food preparation/cooking area shall be at least 50 foot candles measured from counter height.
 - (D) In facilities with building plans approved on or after April 1, 1999, corridor lighting shall equal a minimum of 20 foot candles measured from the floor.
 - (E) In facilities with building plans approved on or after April 1, 1999, task lighting in the dining room shall equal a minimum 25 foot candles without light from windows measured from table height.
- (e) Call System
- (A) A two-way voice interactive call system shall be provided, capable of being turned off by the resident, connecting resident units to the care staff center and/or staff pagers.
 - (B) A manually operated emergency call system shall be provided at each resident bathroom and central bathing rooms.
 - (C) An exit door alarm or other acceptable system shall be provided for security purposes. It may be combined with the call system.
- (f) Telephones
- (A) Resident Phones. Each unit shall have at least one telephone jack to allow for individual phone service.
 - (B) Public Telephone. There shall be an accessible local access public telephone in a private area that allows a resident or another individual to conduct a private conversation.
- (g) Television Antenna or Cable System. In facilities with building plans approved on or after April 1, 1999, a television antenna or cable system with an outlet in each resident unit shall be provided.
- (h) Smoke Detectors. An interconnected smoke detection system is required, including an annunciator panel, meeting requirements of the Oregon Structural and Fire and Life Safety Code and Oregon Electrical Specialty Code.

411-056-0055 Exception and Variance

- (1) The Division may grant exceptions to OAR Chapter 411, Division 056. Exceptions shall not be granted which are judged to be detrimental to the residents. The facility seeking an exception shall submit to the Division, in writing, reasons for the exception request.
- (2) No exception shall be granted from a regulation or provision of these rules pertaining to the monitoring of the facility, resident rights, and inspection of the public files. Exceptions shall not be granted by the Division without prior consultation with agencies involved.
- (3) Exceptions granted by the Division shall be in writing and be reviewed periodically.
- (4) An individual exception shall be required for each resident who chooses to share a unit with someone other than his/her spouse to assure personal choice.

411-056-0060 Monitoring, Inspections and Investigations

- (1) The facility shall cooperate with Division personnel in surveys, monitoring, inspections, complaint investigations, planning for resident care, application procedures and other necessary activities.
- (2) Staff of the Division or its designee may visit, inspect and monitor assisted living facilities at any time, but no less often than once every two years, to determine whether it is maintained and operated in accordance with these rules.
- (3) Facilities not in compliance with these rules may be required to submit a plan of correction that satisfies the Division within the time frames specified. The Division may impose sanctions for failure to comply with these licensing rules.
- (4) Division staff shall have full access and authority to examine and copy facility and resident records. Division personnel may conduct private interviews with residents, staff and other witnesses.
- (5) Representatives from the State Long Term Care Ombudsman office and each designee shall have the right of entry and access to records pursuant to ORS 441.117, 441.109 and OAR 114-005-000, 114-005-010, 114-005-0030.
- (6) The State Fire Marshal or his/her authorized representative(s) shall be permitted access to the facility and records pertinent to resident evacuation and fire safety.
- (7) A copy of the most current inspection survey shall be made available for the public by the facility. A sign shall be posted in public view, stating the survey is available upon request.
- (8) Standards shall be followed for investigations.
 - (a) The Division shall cause an investigation to begin;

- (A) Within two hours if a complainant alleges a resident has been injured due to abuse, any resident's health or safety is in imminent danger, or a resident has died or been hospitalized due to abuse;
 - (B) By the end of the next working day if circumstances exist which could result in the injury/abuse of a resident.
 - (C) Investigations for all other complaints shall be commenced within five days.
- (b) An unannounced on-site visit will be conducted.
 - (c) All available witnesses identified by any sources as having personal knowledge relevant to the complaint shall be interviewed. Interviews shall be confidential and conducted in private unless otherwise requested by the witness. The investigator shall interview the administrator and shall advise the administrator of the nature of the complaint and give the administrator an opportunity to submit relevant information to the investigator.
 - (d) All evidence and physical circumstances that are relevant and material to the complaint shall be observed.
 - (e) Immediate protection shall be provided. The administrator shall correct any substantiated problem immediately.
 - (f) The investigation shall be completed and the report shall be written within 60 days of receipt of a complaint which includes the investigator's personal observations, a review of documents and records, a summary of all witness(es) statement(s), and a conclusion.
 - (g) Reports indicating the need for a sanction by the Division shall be referred to the appropriate office for corrective action immediately upon completion of the investigation.
 - (h) The Division, through its local offices, will mail a copy of the investigation report to the following people within seven days of the completion of the investigation.
 - (A) The complainant (unless the complainant requests anonymity);
 - (B) The resident(s) involved and any person(s) designated by the resident(s) to receive the information;
 - (C) The facility; and
 - (D) The State Long-Term Care Ombudsman.
 - (i) The report shall treat as confidential the identity of the resident, the complainant, and any witnesses.

- (j) The AAA/SDSD office shall provide written notification informing such persons of the right to give additional information about the report to the Division's local office within seven days of receipt.
- (k) The SDSD/AAA office shall review the responses and reopen the investigation if additional evidence of a violation is received. A copy of the entire report shall be sent to the Division upon completion of the investigation report whether or not the investigation report concludes the complaint is substantiated.
- (l) Investigation reports, including copies of responses (with confidential information deleted), shall be available to the public at the local SDSD/AAA office.
- (m) At any time after receipt of a notice of violation or an inspection report, the licensee or the Division may request a conference. The conference shall be scheduled within 10 days of a request by either party.

411-056-0070 Conditions on License

- (1) Conditions which may be imposed on a licensee include:
 - (a) Restricting the total number of residents;
 - (b) Requiring additional staff or staff qualifications;
 - (c) Requiring additional training of administrator/staff;
 - (d) Requiring additional documentation;
 - (e) Restriction of admissions; or
 - (f) Other conditions at the determination of the Division.
- (2) Conditions may be attached to a license upon a finding that:
 - (a) Information on the application or initial inspection requires a condition to protect the health and safety of prospective residents;
 - (b) There exists a threat to the health, safety, and welfare of residents;
 - (c) There is reliable evidence of abuse, or exploitation; or
 - (d) The facility is not being operated in compliance with these rules.
- (3) The Division shall notify the facility by certified mail when a decision is made to place conditions on the facility license. The condition(s) shall take effect immediately upon receipt of notice or on a date specified in the notice.

- (4) Written notification of impositions of conditions shall be posted with the facility's license in public view near the main entrance of the facility. The notification shall state the reason for the conditions and the facility will be given an opportunity to request a hearing under ORS 183.310 to 183.550.
- (5) If a request for review is made, the Division will review all material relating to the allegation of resident abuse or health or safety violations and to the license condition. The Division shall determine, based on review of the material, whether or not to sustain the condition and shall notify the facility of the decision within 20 days of receiving the request for review.
- (6) If the Division determines not to sustain the decision, the condition shall be lifted immediately. Otherwise, the condition will remain in effect until the Division determines that the conditions leading to the abuse or health or safety violations have been corrected.

411-056-0075 Non-Renewal, Denial, Suspension or Revocation of License

- (1) The Division shall deny, suspend or revoke a license when it finds there has been substantial failure to comply with these rules.
- (2) The Division shall deny, suspend or revoke a license if the licensee fails to comply with a final order of the Division imposing an administrative sanction, including the imposition of a Civil Penalty.
- (3) In cases where an imminent danger to the health or safety of residents exists or if the facility is not in substantial compliance with these rules, a license may be suspended immediately.
- (4) The Division shall not renew a license if the facility is not in compliance with these rules.
- (5) Such revocation, suspension, denial or non-renewal shall be done in accordance with rules of the Division and ORS Chapter 183.

411-056-0085 Marketing and Advertising

- (1) A person may not advertise or market its facility as an assisted living facility, or as providing assisted care, or use the term "assisted" in describing the type of care provided unless the person has obtained or can demonstrate intent to obtain an assisted living facility license from the Division.
- (2) All advertisements shall be consistent with facility policies, these rules, and the Federal Trade Commission in the representation of license status, services, staffing and amenities.

411-056-0090 Civil Penalties

- (1) For purposes of imposing civil penalties, assisted living facilities licensed under ORS 443.400 to 443.455 and subsection (2) of ORS 443.991 are considered to be long-term care facilities subject to ORS 441.705 to 441.745.
- (2) For purposes of this rule, the following definitions apply:
 - (a) "Person" means a licensee under ORS 443.420 or a person who the Senior and Disabled Services Division Administrator or his/her designee finds should be so licensed but is not, but does not include any employee of such licensee or person;
 - (b) "Direct patient care or feeding" means any care provided to or for any resident related to that resident's physical, medical, and dietary well-being as defined by rules of the Oregon Health Division; and
 - (c) "Resident rights" means those rights identified in OAR 411-056-0010;
- (3) The Division shall exercise its authority under ORS 441.705 to 441.745, and thereby issues the following schedule of penalties applicable to assisted living facilities:
 - (a) A Class I violation exists when there is noncompliance involving direct resident care or feeding, adequate staff, sanitation involving direct resident care or resident rights. A Class I violation may result in imposition of a fine for first and subsequent violations of no less than \$5 and no more than \$500 per occurrence per day not to exceed \$6,000 in any calendar quarter.
 - (b) A Class II violation exists when there is noncompliance with the license requirements relating to a license required, the license requirements relating to administrative management, personal services (care) and activities. Class II violations may result in imposition of a fine for violations found on two consecutive monitoring of the assisted living facility. The fine may be no less than \$5 and no more than \$300 per occurrence per day, not to exceed \$6,000 in any calendar quarter.
 - (c) A Class III violation exists when there is noncompliance with the license requirements relating to building requirements, resident furnishings, and move-out criteria. Class III violations may result in imposition of a fine for violations found on two consecutive monitoring of the assisted living facility. The fine may be no less than \$5 and no more than \$150 per occurrence per day not to exceed \$6,000 in any calendar quarter.
- (4) In imposing a penalty pursuant to the schedule published in this rule, the Administrator for the Senior and Disabled Services Division or a designee shall consider the following factors:
 - (a) The past history of the person incurring a penalty in taking all feasible steps or procedures necessary or appropriate to correct any violation;

- (b) Any prior violations of statutes or rules pertaining to assisted living facilities;
 - (c) The economic and financial conditions of the person incurring the penalty; and
 - (d) The immediacy and extent to which the violation threatens the health, safety, and well-being of residents.
- (5) Any civil penalty imposed under ORS 443.455 and 441.710 shall become due and payable when the person incurring the penalty receives a notice in writing from the Administrator of the Senior and Disabled Services Division or a designee. The notice referred to in this section shall be sent by registered or certified mail and shall include:
- (a) A reference to the particular sections of the statute, rule, standard, or order involved;
 - (b) A short and plain statement of the matters asserted or charged;
 - (c) A statement of the amount of the penalty or penalties imposed; and
 - (d) A statement of the party's right to request a hearing.
- (6) The person to whom the notice is addressed shall have 10 days from the date of mailing the notice in which to make written application for a hearing before the Division.
- (7) All hearings shall be conducted pursuant to the applicable provisions of ORS Chapter 183.
- (8) If the person notified fails to request a hearing within the time specified in ORS 441.712, an order may be entered by the Division assessing a civil penalty.
- (9) If, after a hearing, the person is found to be in violation of a license, rule, or order listed in ORS 441.710(1), an order may be entered by the Division assessing a civil penalty.
- (10) A civil penalty imposed under ORS 443.455 or 441.710 may be remitted or reduced upon such terms and conditions as the Administrator of the Senior and Disabled Services Division considers proper and consistent with the public health and safety.
- (11) If the order is not appealed, the amount of the penalty is payable within 10 days after the order is entered. If the order is appealed and is sustained, the amount of the penalty is payable within 10 days after the court decision. The order, if not appealed or sustained on appeal, shall constitute a judgment and may be filed in accordance with the provisions of ORS 18.320 to 18.370. Execution may be issued upon the order in the same manner as execution upon a judgment of a court of record.
- (12) A violation of any general order or final order pertaining to an assisted living facility issued by the Administrator of the Senior and Disabled Services Division is subject to a civil penalty in the amount of not less than \$5 and not more than \$500 for each and every violation.
- (13) Judicial review of civil penalties imposed under ORS 441.710 shall be as provided under

ORS 183.480, except the court may, in its discretion, reduce the amount of the penalty.

- (14) All penalties recovered under ORS 443.455 and 441.710 to 441.740 shall be paid into the State Treasury and credited to the General Fund.

411-056-0095 Criminal Penalties

- (1) Violation of any provision of ORS 443.400 to 443.455 is a Class B misdemeanor.
- (2) In addition, the Division may commence a suit in equity to enjoin operation of an assisted living facility:
- (a) When an assisted living facility is operated without a valid license; or
 - (b) After notice of revocation has been given and a reasonable time has been allowed for placement of individuals in other facilities.

Appendix B: Oregon's Long-Term Care Options

Respite Care

Respite Care services give families and other care givers temporary relief from providing care for frail adults. Companionship, light assistance, recreational activities, and security are provided in a client's home, out of home in a group setting, or overnight in a residential setting. Respite care fosters a healthier quality of life for both the care giver and care receiver.

Adult Day Services

Adult day services can help people with physical and cognitive impairments remain independent. They are offered in a variety of centers around Oregon. People with chronic or progressive health problems can be served by adult day services; the clients most often served in this setting have difficulty performing familiar daily tasks, have lost initiative, motivation or memory, or need a safe environment and supervision. Adult day programs typically provide socialization, reminiscing, recreational exercise, counseling, support groups, information, nutritious meals and snacks, health monitoring, and art/music therapy. Some day centers also offer nursing, physical therapy, and personal care.

In-home Services

This is the most rapidly growing and popular part of Oregon's Long-term care System. Seniors and people with disabilities can receive services in their own home. Those services include help with personal or health care needs and housekeeping. Nursing services and home delivered meals can also be arranged. In-Home Services include:

- Meal Preparation
- Shopping and Transportation
- Home Health Services
- Assistance with Medication
- Housekeeping and Laundry
- Medication Management
- Money Management
- Assistance with Medical Equipment
- Dressing and Personal Hygiene Assistance

Adult Foster Homes

Adult foster homes are private residences licensed to provide care to five or fewer residents. They offer room and board, personal care from a care giver in the home 24 hours a day. Planned activities and medication management are available, and some provide transportation services, private rooms, or nursing services. A wide variety of residents are served in adult foster homes, from those needing only room, board and minimal personal assistance to those residents needing full personal care and skilled nursing tasks. The care provided depends on the client's needs and the skills, abilities, and training of the provider. Adult foster homes are inspected, licensed, and monitored by the state or by the local Area Agency on Aging (AAA).

Assisted Living Facilities

Assisted living facilities have six or more private apartments. They are fully wheelchair accessible and offer full dining room services, housekeeping and call systems for emergency help when needed. Registered nurse consultation is available. Physical care and additional health care supervision and assistance can be provided in the client's own apartment. Organized activities and transportation are available. These facilities follow guidelines that promote the residents' right to privacy, personal choice, and independence. Assisted living facilities are inspected, licensed and monitored by Senior and Disabled Services Division.

Residential Care Facilities

Residential Care Facilities serve six or more residents. They offer room and board with 24-hour supervision, assistance with physical care needs, medication monitoring, planned activities, and often transportation services. Some offer private rooms; some registered nurse consultation services. They are inspected, licensed and monitored by SDSD.

Nursing Facilities

Nursing Facilities provide nursing care on a 24-hour basis in a more institutional environment. They provide skilled care, rehabilitation, and end-of-life care. Nursing facilities are required to have licensed nursing staff in the facility 24 hours per day. Nursing facilities are most appropriate for people who need a more protective setting. Many residents have medical and behavioral needs that cannot be met in other care settings. Nursing facilities are inspected, licensed, and monitored by the state, in compliance with both state and federal regulations.

The CHAIRMAN. We thank all four of you for your fine testimony. I am going to start with Ms. Allen of the General Accounting Office, and this deals with your methodology and findings. First, could you begin by describing how the General Accounting Office chose the four State sample that it chose? How representative is it of assisted living in other States? Then can you tell us how extensive the evidence of problems you found is regarding quality of care and consumer protection?

Ms. ALLEN. We chose these four States because each of them have a large number of assisted living facilities and they represent four distinct areas of the country. So we were trying to achieve geographic diversity.

We specifically selected Florida and Oregon because they license facilities as assisted living facilities and they also use Medicaid waivers to help reimburse facilities for covered services for Medicaid-eligible residents. In contrast, California and Ohio do not have a separate licensing category for assisted living facilities and they do not use Medicaid waivers to fund care in these facilities.

So our work in these four States clearly illustrate the variety of the types and sizes of facilities that are participating in assisted living. They typify the types of residents that are served and the varying approaches to oversight. But based on these four, we cannot generalize to other States or to the nation as a whole.

With respect to the seriousness of our findings, I would like to start by saying that we did see quite a range of outcomes in our findings which were based on State inspection reports and other oversight efforts, such as that identified by the ombudsman. For example, we identified that almost 40 percent of the facilities that we sampled had no deficiencies identified in the areas of quality of care or consumer protection. I think that is an important point to make.

But at the same time, we did, learn by analyzing State data, that over one-fourth of the facilities had five or more verified problems, and perhaps more importantly, one in 11 facilities had ten or more quality of care problems. Now, I think the natural question is, how serious is that? Is that something that we should be alarmed about? How does it compare to other settings of long-term care?

Unfortunately, I think we cannot answer that at this point in time. We do not have comparable or uniform standards across States. We do not have comparable survey data. So it is difficult to draw conclusions.

But what we did learn from the information we analyzed is that the findings reflect a range of seriousness. In some cases, they are serious enough that we saw examples where residents ended up in a hospital with dehydration, decubiti, and in some cases, death.

In other cases, some of the deficiencies that are identified and are included in our data include simply areas where certain things were not documented, where perhaps there was no documentation that particular training had been provided to caregivers. In that case, it certainly raises questions about the capacity of the facilities to provide appropriate care.

I think in combination, then, perhaps more needs to be studied about just how serious this is.

The CHAIRMAN. Your agency's sample of facilities illustrates a very wide variety of types and sizes of facilities. Could you comment on the preponderance of either the quality of care problems or the consumer protection problems identified in your report of quoting the facility types, and if you cannot do that, what limitations does that place on growing generalizations about the quality of care in assisted living facilities?

Ms. ALLEN. We did not analyze by sector or by type of facility on a statistical basis the correlations between quality, for example, and facilities. One thing that we did note, though, is that the number and types of problems that are identified in these facilities can often depend on quite a number of factors unique to each State.

For example, the frequency of verified problems may be higher in a State where there are more licensing standards, more frequent inspections, or more agencies involved in oversight. This is certainly the case, for example, in Florida and Oregon, where they have not only the State licensing agency, but they also have ombudsmen who are very active, and in those two States, they also use adult protective services and the Medicaid fraud control unit.

In cases such as that, there could be a tendency to have a higher frequency of reported problems, but that is not to say necessarily that the quality is poor if there are more findings. It simply means that there are other types of mechanisms in place.

The CHAIRMAN. Senator Breaux.

Senator BREAUX. I thank all the panel members for their work and their help in making our hearing more informative. I was looking at information about my own State of Louisiana. We have now apparently rules that are in place regulating the State assisted living facilities. The regulations basically deal with the things we would expect it to deal with, also with the staffing ratios and the qualifications for the staff, the training that they have to receive, the background checks that have to be done, licensing by the State, et cetera.

I am concerned that we have 50 different sets of rules and standards, all pretty much the same and addressing the same things, but are really very different. Fifty different standards as opposed to maybe one Federal standard. Can I have some comment from any of you about that concern?

I also, at the same time, have been impressed by the type of complaints that we hear about assisted living facilities, which are not federally regulated, because these complaints are the same complaints that we hear with regard to nursing homes, that are federally regulated. So the argument that says we will solve all this by just having a set of Federal regulations is not correct. It is not going to solve the problem. We will still have the same problems. But at least you have one set of standards that everybody could be measured by.

Can I have just some comments from any of you about the feasibility of 50 different sets of rules and regulations versus one? Ms. Allen.

Ms. ALLEN. The issue that you raise, Senator, is a very difficult issue, especially at present because this industry is funded primarily by private resources and is overseen by the States. In an industry such as this, where there is such a preponderance of pri-

vate resources, typically, we would look to competition and other market forces to play the paramount role in responding to consumer demand and preferences.

Senator BREAUX. How many States have rules and regulations in place?

Mr. MOLLICA. They all do. They just call them different things.

Senator BREAUX. So we really have 50 different sets of standards and procedures for assisted living facilities?

Mr. MOLLICA. Yes.

Senator BREAUX. So we do have regulations, even though it is privately funded, for the most part. You have regulations. They are all on the State level. So my question is not whether you have them but whether we should have 50 different sets of rules and regulations versus one set of standards.

Mr. MOLLICA. I think that if there were a set of Federal regulations, you still might have 50 different sets of additional State regulations. I also think that regulation alone is not sufficient to attack these issues. A combination of regulation, and oversight is needed. The good part about the GAO findings is that these problems were identified through the States' existing oversight practices, and while it was beyond the scope of the study, my question was what was the follow-up? What happened when the State found these problems?

I think that we need to pay attention to staff training and salaries, as well as the regulation and the oversight and also the enforcement activity. I think that if there were perhaps an independent accrediting body, in addition to state regulations like there is in other areas, that that might emphasize market forces to set higher quality standards. If there were some accrediting body that private facilities could go to voluntarily to meet higher standards, I think that might help give consumers a better comparison.

Senator BREAUX. That is what we were talking about up here. The information is what is important, if we have some central repository of information on these of facilities that people could look to, like I can look to when I am looking to purchase the microwave or anything else that Consumer Reports gives us all the information on. I cannot find that, generally, for health care delivery systems.

Ms. Hannum, what is your thought about this?

Ms. HANNUM. I have very mixed thoughts, actually. The challenge is, we have to decide what community-based care can do and what it cannot do. You have States such as Oregon, who have gone the outer limit here. We really believe in allowing people to choose where they want to live, very much. We really believe in packaging services to bring to that care setting. We have a Board of Nursing that has embraced nurses teaching lay caregivers all kinds of things, so we are able to put those services together.

Other States do not necessarily feel that way. I am not sure the Federal Government would feel that way. What we would be concerned about is a set of regulations that are not unlike nursing facility regulations, which, frankly, we do not think would serve this model of care well.

So while I very much appreciate your concern, Senator, about good access to information, having a one-stamp-fits-all approach, I

think, is going to create problems. We do support having some way to compare quality among facilities.

Senator BREAUX. Dr. Hawes, any comments?

Ms. HAWES. Well, I will be the voice in the wilderness here, I think. We recently completed a study for ASPE that looked at the regulation of board-and-care homes in ten States. In many States this included assisted living, and in our study included assisted living. We ranked all 50 States in terms of their regulatory, for lack of a better word, stringency. What we found is that the States that had more extensive regulatory systems had better quality of care.

Now, what I mean by more extensive regulation is not the OBRA 1987 regulations for nursing homes. It is that they required licensure of every facility. Oregon, by the way, was one of those in that top group. They required licensure. They had clear standards. And most of all, they enforced the regulations that they had. They had a range of enforcement remedies and they used them.

I think that the committee's hearings on nursing home regulation have shown pretty dramatically that the main thing missing now in nursing home regulation is not the standards, it is the enforcement of those standards when homes are not in compliance.

Senator BREAUX. On that point that you just talked about, that some States have good programs, I take it that that means that other States do not have as good programs. So you have a huge difference in the type of assisted living facilities that are operating out there. I guess the question is, does it call for the need for a single Federal standard with Federal regulations and enforcement in order to ensure that everybody has the same high quality as some States apparently do? Or can we achieve a high level of quality every where by letting the States do it? I mean, our question here is, do we do something from a Congressional standpoint in this area or do we just encourage the States to do it themselves or what?

Ms. HAWES. It is the horns of a dilemma. It is a new industry; we want to encourage innovation; and there is no clear evidence about which regulatory model works best in terms of producing the highest quality. So we are sort of at this awkward stage where we understand that there are some problems, but there is a lot of variability among ALFs and among state regulatory structures.

One of the things that you could do is probably some kind of, well, I do not know what to call it, something comparable to truth-in-lending, that there be some standard for what ought to be in contracts, what information ought to be available to consumers about the price, the services, the retention and discharge criteria, things that consumers need to know in making judgments.

And maybe the second is that you could expand funding for the ombudsman program so that there are advocates in the community who can help families make the decision and deal with quality problems when they arise.

Senator BREAUX. Thank you.

The CHAIRMAN. Thank you all.

Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman. I think this is an excellent panel that has really laid out a number of the most important issues we have.

One question for you, Cindy, with respect to the surveyors, how do you see the difference in what surveyors do with respect to nursing homes as opposed to how surveyors go about the task of looking at assisted living facilities?

Ms. HANNUM. Well, actually, Senator, in Oregon, we use the same surveyors to do both, but we found that that has some problems. We have had to train them in different ways to deal with the community-based care regulations and also the way that they approach the survey. So we use surveyors, but take them for six-month periods of time and have them work on community-based care, and then they will go back to nursing facility care.

There are certain common things, such as wanting to interview residents, such as wanting to make sure we look at care plans, to look at the case mix to make sure we know how impaired people are, but there are different standards and different approaches. So we have had to do careful training in that regard.

Senator WYDEN. I think it is an important distinction, because while the inspectors are the same, one is a medical model and another one is a different kind of concept.

Ms. HANNUM. Right.

Senator WYDEN. A question for you, Dr. Hawes, and it really touches on what your associate said earlier about an accrediting effort. I think it was Mr. Mollica who talked about that. My concern about those kinds of approaches is that the majority of facilities, which I think are trying to do a good job and a conscientious job—as I say, I spent the weekend with my mother in one that does a very sensitive and careful job—they are going to be fine under those approaches.

The problem is, however, we found a number that are not adhering to those kinds of standards and so my concern about going with an accrediting kind of approach is that what we will do is we will put a variety of pretty good outfits through their paces and then we will not be picking up on the ones that are a problem, which leads me really to you, Dr. Hawes, and a question of sort of how do we begin from here?

I think you heard us all talk about information. You can have a debate about a lot of health issues in this country, but the idea that a third of these programs that we surveyed essentially kept the consumer and their families in the dark is absolutely unacceptable, so I think you are going to see us make some changes with respect to information.

My question would be, working from here, do you think it would make sense for this committee to work to try to come up with a model that could be pursued at the State level with respect to certain kinds of core protections for consumers and families and try and do it in a way that was flexible enough to pick up on the differences between States, because I think you are going to see a reluctance to just go to a one-size-fits-all Federal cookie cutter approach. I know that I would be very reluctant to go that route because I have seen what happens in Coos Bay, OR, does not necessarily work in the Bronx.

But I think your point is a very thoughtful one in terms of sort of how we begin, and I wonder if we could not, on the basis of your research and what the GAO has done, perhaps come up with a

kind of model that could be pursued at the State level with some core kinds of protections and make sure that there is enough flexibility so that different States could adjust it. Does that make sense?

Ms. HAWES. I think that is a terrific idea. Bob and I get calls from the States all the time because of the study we are doing. States are struggling with what to do, especially since the population in these facilities will become increasingly impaired over time, and not just gradually but fairly rapidly, which dramatically increases the stakes for regulatory agencies. So I think anything you can do to support the efforts of the States to have good consumer protection and good disclosure laws in place would be enormously helpful.

I agree with you about accreditation. It is not that accreditation is not a terrific thing for facilities that choose it, but we are likely to then create a real two-tiered system of assisted living, and I am not sure that is what at a Federal level you want to do.

Senator WYDEN. Your point is a good one. The danger with two tiers here is that the other tier, which does not consist of the majority of facilities that are trying to be responsible, could really produce the kinds of situations that we heard about earlier, where folks were physically abused and the like.

All of you have been very helpful and we look forward to working with you. You GAO folks started this with me more than three years ago and we had the good fortune of getting Chairman Grassley and Senator Breaux and I think you all have done a first rate job. We now have two good reports, the first report which shows the differences in the 50 States in the definitions. That had not been done. Now we have got a report that begins to outline the quality of care issues and just know we appreciate your professionalism.

Ms. ALLEN. Thank you.

The CHAIRMAN. Dr. Hawes, your testimony states that the most common type of assisted living facility closely resembles the traditional board-and-care setting. This model, which you describe as low privacy, low service, in fact, represents 58 percent, as shown by your chart. Yet on the next panel, we are going to hear from leading industry providers who represent more of what is described in your sample as high service, high privacy.

Could you comment on the two different types of facilities, because it appears to me that the growth is occurring in what is considered high service, high privacy, yet the opposite type of facility, low service, low privacy, is a much larger part of your sample.

Second, will a consumer who is looking for high service, high privacy, be able to quickly identify which facility in a certain community fits into that niche?

Ms. HAWES. I think it is important to say that the people who belong to the professional trade associations are not a nationally representative sample of the places that call themselves assisted living, while ours is a nationally representative sample of assisted living facilities. So the ASPE study represents the facilities that call themselves assisted living nationwide.

Part of the problem that Dr. Mollica highlights in his report is that in many States, virtually anyplace can call itself assisted liv-

ing. So for the consumer, the challenge of knowing which of those ALF types a facility fits into is non-trivial.

When we interviewed residents and family members about how they defined quality and what they were looking for, family members often said that they selected a facility based on how nice it looked, that it was an apartment, that it was a pretty campus, that it did not look like a nursing home. But six months later, what they really wanted was staffing and services, staff qualifications and low staff turnover.

So part of the solution is educating consumers, as you pointed out, about what they need to know and what they need to ask, and part of it is ensuring that facilities make that information available. Hardly any facility reveals, for example, what its staff turnover is, yet many people think that is an excellent indicator of quality of care.

So I think consumers do not have an easy time. They need to ask really specific questions: "will my mother be retained if, will you provide care if." For example, facilities will say, oh, yes, we accept residents who are incontinent, and what they mean is a resident who can manage his or her own supplies and change her own sheets. What the daughter means is, "when my mother's cognitive impairment progresses to where she no longer knows where the bathroom is, will you help her get to it?"

So it is a serious issue of understanding what the trajectory of your relative's needs is what services the facility will provide. I think, by and large, many facilities are not providing that kind of detailed information in helping families understand what they are going to need in the future.

The CHAIRMAN. Ms. Allen, I was wondering, from your report, it has been criticized on the grounds that the problems you identified are not really found or frequently found in the high-end more recently established facilities. Could you comment?

Ms. ALLEN. Yes. What we can say is that we did not stratify our data, nor did we report along the lines of the size of facility, or along other dimensions, such as profit or nonprofit status.

But what we can say from our work in looking at the State-reported data, as well as our own visits in many facilities, is that we found high quality in all facilities, both large and small, and, likewise, we found quality problems in all facilities, the purpose-built as well as the small. So these concerns are throughout the industry.

The CHAIRMAN. Mr. Mollica, have you tracked Medicaid and SSI payments to facility types? In other words, among the different types of facilities described by Dr. Hawes, are you able to say which types of facilities are receiving Medicaid funding?

Mr. MOLLICA. We can only tell whether Medicaid is available in a State, and generally, if Medicaid is available, they have a much greater opportunity to support facilities that have rates upwards of \$2,000 to \$2,200. The State of Washington, for example, provides payments that would total up to \$2,200.

In those States where only SSI is available, it is less likely that they are going to be able to provide either a quality living arrangement or certainly the services that somebody who is frail and is aging in place is going to need.

The CHAIRMAN. Ms. Hannum, I will submit one question to you for answer in writing.

I will turn now to Senator Breaux.

Senator BREAUX. I do not really have any other questions. I think that the primary concern is that we have adequate information for people to make informed decisions about which facility to select for their relatives, parents, friends, or people who they care about.

With regard to an ombudsman located in each of the States, is that complaint process working? Is there any publication of the ombudsman's work each States that would be helpful to the average person in selecting the facility that they would want their parents to be in? I guess the question is, is the ombudsman system in place to oversee assisted living facilities, and is it working in an effective fashion or not?

Ms. ALLEN. Ombudsmen are present throughout the States and can be an excellent resource for people to go to. We did not evaluate the effectiveness of the ombudsmen. My understanding is that they probably vary in terms of their presence, and their levels of effort at the state and local district levels.

We did not evaluate their effectiveness, but much of the information in our report is based on information that was collected from the ombudsmen. They are there, they are in the facilities, they are very responsive. Some might even say they are a little too aggressive sometimes. But the facility knows that when they are there, that they are someone to be reckoned with and they are an advocate on behalf of residents, particularly the ones who are more frail.

I think that one thing we need to keep in mind, that we have heard today, is that many residents may enter facilities relatively healthy, maybe only need a little assistance. But as their health conditions decline and their needs increase, they may also be in a situation where they do not have family or friends to advocate on their behalf, and it is under those situations that other presence like the ombudsmen is very important to be there on their behalf.

Senator BREAUX. Dr. Hawes, any comments?

Ms. HAWES. Yes. We did a report for the Institute of Medicine about a survey of ombudsmen programs about this very issue. One of the things we found is that ombudsmen have responsibilities a mile wide and resources an inch deep. They really are primarily responsible for nursing homes. So while they have technical responsibility for board-and-care and assisted living, they do not really have the resources in many States, unless the States provide substantial additional funding.

Cleveland, for example, has for 20 years had ombudsmen who were very active in board-and-care homes but that is a real exception across the country.

So I think they have a real capacity to be an important resource, but probably not the level of resources available from the Administration on Aging and the Older Americans Act that they need to expand, particularly since assisted living is growing so rapidly.

Senator BREAUX. Does anyone else have a comment? [No response.]

I guess the question is, do the ombudsmen make their information available to the public? Does the general public in a State know that when they go out to select a particular assisted living facility, that there is an ombudsman out there that perhaps they could contact, who could give them information on an adequate facility, a good facility, as opposed to facilities that are bad? Or is this something that just we know about? If the average person does not know about it, it is not helping them. Any comments on that?

Ms. HAWES. In our survey of residents, we found that fewer than 18 percent knew about the ombudsmen program.

Senator BREAUX. So they do not know about it.

Ms. HAWES. In nursing homes, most residents and families know about the ombudsmen program, but in residential care, that knowledge is not widespread.

Senator BREAUX. Maybe just a requirement that everybody be officially informed of the fact that there is an ombudsman when they come into the place, would be useful. It could tell them—if you have a complaint, here is the person to complain to, and that could be helpful. Thank you.

The CHAIRMAN. Thank you, Senator Breaux.

Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman. Just one other question, Mr. Chairman.

Dr. Mollica, you have done a fair amount of research with respect to Medicaid and low-income services for older people. I am troubled that we still do not have very many good options for bringing together those folks and expanding services to low-income people under the assisted living umbrella. Those are people, of course, who cannot vote with their feet, either. If we do a lot of what we are talking about here today in terms of getting information to them, it is going to be hard for a lot of those people to have other options. Do you have any recommendations at this point for the Congress on expanding this?

Mr. MOLLICA. The flexibility within the Medicaid waiver program is there and States like Oregon have taken good advantage of it. I think they have about 2,100 residents, 30 percent of the residents are supported through Medicaid. Other States have been coming on and adding Medicaid coverage, but the actual participation is very low and there might be several reasons for that.

One is that the rates, even though it is covered, may not be sufficient to interest facilities in contracting with Medicaid.

Another concern is if the rates are adequate today, there is a concern among the industry that when State budgets get squeezed, maybe those rates will start to not be as adequate as they might be today.

I think a third factor is that with the demand that there is in the private market, many facilities do not need to contract with Medicaid as long as their units are full. As the supply expands, they might be more interested in contracting with Medicaid as they have more competition and are not able to keep their occupancy rate up as high.

I think that State officials need to really explore not only assisted living as an option but their whole long-term care system and find where assisted living fits in their whole system. Some

States are concerned about adding a service and whether it will cost them more money by creating a woodwork effect. I personally do not think that is a problem here, but it is something that States do consider.

Basically, the flexibility is there and States, over time, I think, will begin to take more advantage of it as they become more used to this opportunity.

Senator WYDEN. One of the first bills that I wrote as a member of the House was legislation to make it easier to use Medicaid institutional dollars for in-home kinds of services, but I get the sense that you think we ought to really create a sort of continuum of care that would allow for Medicaid dollars to be used for all of the various options for low-income seniors, and I assume that that would include a variety of other things besides assisted living, things like adult day care and a variety of other approaches, is that right?

Mr. MOLLICA. The more flexibility and the broader array of options, I think the more choices it gives consumers and the more flexibility it gives to States to create a full array of options.

Senator WYDEN. Are there still obstacles in terms of getting some of those waivers to use the money in the flexible way you are talking about?

Mr. MOLLICA. The waiver process is fairly streamlined and nearly every State has one. However, making the program an optional state plan service rather than requiring waivers would help. I think the biggest issue now is States getting the money for the State match. We heard in Florida about the limited number of slots. I think for a State the size of Florida, they only have 500 waiver slots for assisted living and that is not even a rounding error, it is so small. So States have some trouble finding amongst their other priorities, just like Congress does, finding money to put up for the State match in order to expand their services.

Senator WYDEN. On the basis of this hearing and on the basis of the growth we are seeing, everybody in government had better make this a priority, and you all have made that case very well.

Thank you, Mr. Chairman.

The CHAIRMAN. I do not have any more questions, but I am going to explore with some of you something in writing. I was reminded at this hearing that we might tend to think that this is just a situation that people in urban America need to be concerned about. We have got to be aware of the fact that this industry is expanding also in rural America, and so I would ask questions along the lines of any special challenges there when it comes to all of the other aspects that we have explored in this particular hearing. So thank you all very much for participating.

I am going to call now our last panel. The first witness on the last panel will be Philip Downey, vice president of Planning, Development, and Regulatory Affairs for Marriott Senior Living Services. This Marriott organization is a member company of the American Senior Housing Association.

Next, we will hear from Reverend Dean Painter. Reverend Painter is president and CEO of Eaton Terrace Group in Colorado. They are a member of the American Association of Homes and Services for the Aging.

Next, William Lasky, president and CEO of Alternative Living Services, and also a member company of Assisted Living Federation of America.

Last, we will hear from Robert Lohr, who is founder and president of Peridot Enterprises, who is a member company of the National Center for Assisted Living.

Each of these witnesses bring much expertise in developing marketing, financing, and managing assisted living facilities. I thank you all for your participation. We will start with Mr. Downey.

STATEMENT OF PHILIP J. DOWNEY, VICE PRESIDENT OF PLANNING, DEVELOPMENT, AND REGULATORY AFFAIRS, MARRIOTT SENIOR LIVING SERVICES, BETHESDA, MD, ON BEHALF OF THE AMERICAN SENIORS HOUSING ASSOCIATION

Mr. DOWNEY. Thank you, Chairman Grassley. Senator Breaux, Senator Wyden, good afternoon. I work for Marriott Senior Living Services. We are one of the largest operators and providers of seniors' housing in the United States today. We currently operate over 20,000 units, we have experience in 29 States, and 8,200 units of our portfolio are assisted living.

I am also here on behalf of the American Senior Housing Association. We represent 400 of the most prominent owner operators of senior housing and assisted living in the United States today.

I have been invited here to primarily speak about the topic of disclosure. We have heard a lot about it from other witnesses so far, and hopefully, you will not be surprised to hear us say that we heartily agree that disclosure is a critical topic and it is a top priority of Marriott. It is a top priority at our associations. We are committed to provide thorough, accurate, and honest information to our customers.

We believe that consumers cannot fully benefit from this new option called assisted living unless they are fully informed. For this reason, our two prominent industry associations, the American Senior Housing Association and the Assisted Living Federation of America, took a major leap forward in 1998 in developing the Assisted Living Consumer Information Statement, which I think you have a copy of in your package.

Our goal in developing this statement is to provide consumers with a consistent set of information so they can make the decision that is right for them. Our intent is to encourage all our member facilities to complete this statement so consumers have a ready and comparable base of information.

The information should help them answer the big questions, some of which you have heard other witnesses talk about. What kind of services are available to me in your facility and exactly what price will I have to pay for those services? If my needs change, are more intensive services available? How will my price change if I do need more care? Will I ever be required to move out? Under what conditions will I be discharged? How will that be managed? How will it be communicated to me and my family?

The information statement is a three-page form which essentially addresses these and other questions. Specifically, if completed, it would provide the range of services, the range of fees, the life safe-

ty feature in the building, the specifics on licensure, and the specific discharge criteria that the facility operates under. We have already distributed over 5,000 of these documents and we believe that the widespread use will be an enormous step forward in consumer education.

At Marriott Senior Living, we also strive to have all communication channels aligned to achieve clear communication with our customers on the key issues. Our sales and marketing collaterals explain the range of services and the level of care pricing structure. Our counselors and care managers are well trained and they clearly explain the functional assessment process, how we create the wellness plans, and how changes in levels of care are managed and communicated.

As others have noted, the most important disclosure channel is probably the residency agreement itself. This is our binding contract between the resident and the provider. I would note that in most States, their regulations specifically articulate exactly what needs to be included in the residency agreement. Many States actually review and approve the residency agreement prior to a provider being able to use that, and in general, we have no problems with these regulations.

Our residency agreement at Marriott is written in plain English. It clearly explains the limits of services that are provided, how our service plans are established, the process we use to change those service plans, how pricing will change when those service plans are changed, and the exact conditions for discharge. We also have part of that residency agreement this statement on resident rights and the grievance procedure. The residency contract is provided to all customers upon request when they express any interest in making a reservation at our community.

I guess I would close by saying that if assisted living is to live up to its promise, again, all consumers must be fully informed. Marriott and our associations are fully committed to meet that challenge and we invite any feedback you might have on how we might be able to do a better job in that area. That concludes my remarks.

[The prepared statement of Mr. Downey follows:]



**The Hallmarks of Assisted Living
Consumer Choice and Education**

Testimony of

Philip J. Downey
Vice President of Planning, Development and Regulatory Affairs
Marriott Senior Living Services
Bethesda, MD

before the
Senate Special Committee on Aging

April 26, 1999

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Testimony of Philip J. Downey

Chairman Grassley, Senator Breaux, and members of the Committee, my name is Philip J. Downey. I am Vice President of Planning, Development and Regulatory Affairs for Marriott Senior Living Services, a division of Marriott International. Marriott Senior Living Services is the second largest operator of senior living in the U.S. Of the 20,000 units we operate in 29 states, 7,000 are assisted living units in a variety of community settings.

It is my pleasure to testify today on behalf of the American Seniors Housing Association (ASHA), which represents the interests of close to 250 of the nation's most prominent professional owners and managers of seniors housing and assisted living residences. ASHA's members are involved in all aspects of the development and operation of housing for seniors, including the construction, finance, and management of close to 500,000 units nationwide.

Overview of Assisted Living

Over the last 15 years a new long-term care alternative called Assisted Living has rapidly evolved in response to explosive demographic growth and growing consumer preference. As a result, today hundreds of thousands of American seniors live in a diverse range of assisted living communities where they receive the care and support they need to age with dignity. The emergence of Assisted Living as the consumer-driven alternative to nursing homes, has changed the long term-care landscape, and greatly improved the range of choices available to the nation's elderly and their families.

While assisted living residents have a diverse range of needs, they generally require help with one or more activities of daily living, or ADLs (e.g., bathing, dressing, toileting) such that they are incapable of living independently and require regular assistance.

Generally, residents in assisted living receive three meals a day; snacks; assistance with ADLs; medication administration; social activities; laundry and housekeeping; 24-hour emergency response, security; and transportation. In addition to providing these core services, some assisted living residences specialize in caring for certain segments of the elderly population, such as persons with Alzheimer's disease. Residences specializing in caring for those with Alzheimer's disease offer perhaps the best example of how assisted living has improved the lives of individuals and their families. Not more than 15 years ago, a person with mild or moderate dementia who needed help with some ADLs, but did not need medical care, had two very limiting choices: 1. move-in with a family member, or 2. live in a sterile, institutional setting such as a nursing home.

The market has responded to the sizable demand for assisted living with a broad range of alternative designs and service delivery models. Residents have the benefit of choosing from small "cottage" type designs of 20-40 units or larger full service models with 100 units or more. Also, there are residences at a range of prices depending on the preferences, needs and budgets of the resident. No matter the setting, the vast majority of assisted living residents (over 90 percent) live by themselves in a private apartment that they furnish with their own belongings. Unlike nursing home rooms, apartments in assisted living often feature kitchenettes, private bathrooms and lockable doors to maximize independence, dignity and personal privacy.

The typical assisted living resident is an 83-year old widow who cannot live independently and needs assistance with two to three ADLs. Approximately half of all assisted living residents have some degree of cognitive impairment. Most live within a 30-minute drive of their adult children and, according to a recent study conducted by the National Investment Center for the Seniors Housing and Care Industries, more than half (52 percent) of all assisted living residents have annual incomes less than \$20,000.

The American Seniors Housing Association estimates that there are currently 6,500 purpose-built, professionally-owned and managed assisted living residences serving approximately 550,000 seniors in the United States. In the past three years alone, ASHA estimates that nearly 1,200 assisted living residences consisting of over 85,000 units have been built.

Hallmarks of Assisted Living: Private Payment and Customer Choice

Customer choice is the driving force for quality in this industry. Rapid and widespread consumer acceptance of assisted living has occurred despite the fact that assisted living is overwhelmingly paid for privately. By comparison, Medicaid alone pays for over 70 percent of all nursing home patient days.

Given the industry's growth and private pay orientation, assisted living operators must consistently provide high-quality housing and services in order to succeed. Indeed, the very nature of the purpose-built, professional assisted living marketplace demands that the needs of its customers come first, since private payors are often the only source of income for assisted living operators. The assisted living residences operated by the vast majority of professional companies exceed most state

regulations in areas related to life safety features; unit size; staffing, training; and resident assessments.

Purpose-Built, Professionally-Owned and Managed

The typical assisted living residence that is reflected in the portfolios of the American Seniors Housing Association's membership has been designed and built for the purpose of providing high-quality assisted living services to frail elderly persons who need assistance with activities of daily living. The preponderance of these state-of-the-art properties have been built in the past five years. The relative newness of purpose-built assisted living residences has provided consumers with highly attractive and safe living environments, as these buildings must comply with stringent state and local building requirements.

Marriott is committed to the highest standards of life safety in our assisted living communities. While our Brighton Gardens are residential in appearance, they are constructed to comply with building code classification "Type 2", Institutional(non combustible), meaning a structural steel and concrete building with fire rated walls, conduit, sprinklers, emergency response systems and other features to ensure that residents are fully protected. In total we estimate these features add \$9-10 per sq. ft. to our assisted living communities compared to standard apartment construction.

Professionally-owned and managed, purpose-built assisted living should not be confused with "board and care" homes, which have existed for decades in this country, serving primarily very-low income persons, including seniors. While there are, of course, some fine board-and-care homes, the board and care industry, much like the nursing home industry, has had a very mixed record with respect to

quality. And, although there are some states that have different nomenclature for board and care homes, it is not uncommon for these properties to be termed and even licensed as, assisted living. The differences in physical plant and life-safety features, staffing, training and overall quality between board and care homes and professionally-owned and managed assisted living residences are significant. Unfortunately, certain studies conducted in the past few years that have examined the assisted living industry have reached spurious conclusions because of samples that inappropriately include both board and care homes and assisted living residences.

State Regulation and Oversight

Despite misperceptions that assisted living has somehow escaped regulatory oversight, the reality is that this industry is well regulated at the state level. For the past three years, ASHA has tracked regulatory and statutory developments related to assisted living in all 50 states. Between 1997 and 1998, 23 states (46%) modified their assisted living statutory/regulatory requirements. Between 1998 and 1999, 30 states (60%) amended their assisted living statutory or regulatory requirements. In the past two years alone, 36 different states passed laws or revised regulations for this industry. ASHA expects that six of the 14 states that have not modified their assisted living regulatory framework in the past three years, will do so before this year ends.

Many state policymakers across the country recognize that there is a better way to meet the long-term care needs of seniors and have set out to chart a wholly different course in long-term care. They do not want to repeat the mistakes of the past that have resulted in highly "institutionalized" settings that are prevalent in nursing homes. Rather, a very purposeful effort has been undertaken by states to individualize and customize long-term care services through the concept of assisted living.

There are many fine examples, such as New Jersey, Arizona, Texas, Oklahoma, and Maryland where new regulations were developed with significant input from providers and consumer advocates. Indeed, one of the hallmarks of assisted living is the *esprit de corps* that has emerged among state regulators, providers and consumers in developing regulations. This broad level of participation has contributed, in large part, to the development of responsible regulations that are flexible and support quality care in a safe living environment.

Overwhelmingly, state legislative and regulatory activity has recognized the unique and important contributions of assisted living for their senior populations. By taking ownership of assisted living oversight, states have the flexibility to create innovative programs that best meet the needs of their seniors while upholding quality standards and taking regional preferences into account. In the end, it is the consumers who are the beneficiaries of state oversight of assisted living.

Industry Efforts to Educate Policymakers and Consumers

The American Seniors Housing Association, in partnership with a wide variety of interested parties, has provided numerous educational tools to state policymakers and consumers concerning quality and consumer protection. A brief summary of several of these efforts follows.

In the spring 1992, ASHA developed a model assisted living act to help state policymakers understand what was, at the time, a new industry. This effort was the first of several industry initiatives to assist state lawmakers and regulatory agencies in creating appropriate regulatory mechanisms to ensure

quality shelter and services for assisted living consumers. The model assisted living act was distributed to every state licensing agency and legislature.

A collaborative effort, initiated in 1995, between ASHA and the American Bar Association's Section of Real Property Probate and Trust Law, Committee on Housing for the Elderly, resulted in the publication of a model Retirement Community Admission Agreement. This guide was prepared for attorneys and consumers to help identify issues that should be addressed and options to be considered in admission contracts. Thousands of copies of this publication have been distributed to consumers and their legal advisors in the past four years.

The Assisted Living Quality Coalition (ALQC), formed in 1996, is an example of an on-going collaborative effort between providers and consumers to offer guidance to states on appropriate quality standards for assisted living. The Assisted Living Quality Initiative, published last August, accomplished two major objectives. First, it developed a system for measuring quality in assisted living by creating a partnership between consumers, regulators and providers. Second, the Initiative provided guidelines to state licensing agencies and policymakers to help develop and refine their assisted living standards.

In 1997, ASHA created a brochure entitled "Assisted Living Residency Agreements, Key Points to Consider when Choosing a New Home." This consumer-friendly brochure provides consumers and their families with two dozen critical questions that should be asked of prospective assisted living providers with respect to services and care; payment and pricing; and other important considerations.

To date, more than 30,000 of these brochures have been distributed free-of-charge by ASHA members to prospective residents and their families.

Most recently, in late 1998 and early 1999, ASHA and the Assisted Living Federation of America, the two largest industry trade organizations, worked together to prepare and distribute the Assisted Living Consumer Information Statement. This three-page form serves as a general guide for assisted living consumers about the care and services provided in different assisted living settings. It provides consumers with uniform information on resident fees and services; move-out and discharge criteria; staffing; and safety features. This project will allow prospective assisted living residents to easily compare one residence to another in order to help make the most informed decision about which assisted living residence will best meet their needs. Copies of the Assisted Living Consumer Information Statement have been distributed to over 5,000 assisted living providers, and are available to the general public on the world wide web at no cost.

Corporate Efforts to Educate Consumers

From Marriott's perspective, the residency agreement is the most important document any resident will receive. That is why we take it very seriously. It is an important document because it covers all of our obligations, our commitments to the resident and their obligations to us. It is the basis for what forms the partnership between Marriott and our residents.

As part of the process of introducing prospective residents to Marriott Senior Living, our staff are trained to review the residency agreement with residents and their families so that they understand the terms and obligations of the agreement. Although most of our residents do not find it necessary

to seek an outside review of the contract, we also encourage residents, prior to move-in, to share the agreement with an attorney.

All states require that the resident and the assisted living residence enter into a written contract. Prior to developing a residency agreement, our Legal department carefully reviews the state specific regulations regarding the residency agreement to insure that we have included all of the necessary elements for the contract to be valid.

At Marriott, our Agreements are written to be clear, readable, specific and cover many areas, several of which are highlighted below:

- the specific services to be provided and the charges for those services;
- the assessment process to be used to determine the resident's level of care
- the amount of staff assistance required to help the resident meet their needs;
- notification procedures when there is a change in a resident's level of care;
- fee schedule, payment schedule, and rate change notification provisions;
- term, transfer, and discharge provisions;
- authorization for records and release of health care records where expressly required or allowed by law;
- responsibilities of the resident;
- resident rights;

In closing, I would again like to thank the Committee for the opportunity to address them today concerning assisted living. As a leader in this exciting industry our focus will remain on providing a quality product for all of our customers. Our efforts to provide that quality go hand-in-hand with our

goal to educate the consumer (and the policymaker) about what assisted living is, what it provides, and how it can be the best possible choice for our nation's elderly.

The CHAIRMAN. Thank you, Mr. Downey.
Reverend Painter.

STATEMENT OF REVEREND DEAN PAINTER, PRESIDENT AND CHIEF EXECUTIVE OFFICER, EATON TERRACE GROUP, LAKEWOOD, CO, ON BEHALF OF THE AMERICAN ASSOCIATION OF HOMES AND SERVICES FOR THE AGING

Mr. PAINTER. Good afternoon, Senator Grassley, Senator Breaux, and Senator Wyden. On behalf of the American Association of Homes and Services for the Aging, I am pleased to present testimony which addresses quality and consumer protection in assisted living.

Twenty-five percent of our members were providing assisted living long before the term became popular. Its roots, in fact, are found in the not-for-profit homes for the aging at the turn of the last century. In Denver, the Argyle has been in business for more than 125 years and has been cited as a best practices model for assisted living in this country.

The General Accounting Office was requested by this committee to look at quality and consumer protection issues in assisted living. While noting some problems in the industry, which we have heard today, the report affirms three basic positive widely-held beliefs about assisted living.

One, a wide variety of models exist, of which we have heard ample evidence this afternoon. We believe that this gives consumers a desirable choice of settings and service options.

Second, State regulation is, in fact, a workable approach for oversight.

And third, consumer education and protection is the key to preserving assisted living's flexibility, accountability, and innovation.

Let me look very quickly at each of these points. In terms of the first, variety, the report indicates that assisted living facilities exhibit a great deal of variety from State to State, within States, and even in local communities and even within the same regulatory framework. In Denver, we have a number of facilities which are Medicaid certified. Every one of them presents a different type of program. There is variety in State regulatory requirements, the services provided, and even the type of physical structure. But variety has driven innovation and it is good for the consumer.

Second, State regulation works. In its investigation, the GAO did not really discover new problems in assisted living. Rather, it disclosed problems, many of which had already been identified by State agencies.

Third, and most importantly, a commitment to consumer protection is truly required. If providers want to maintain the variety and flexibility for which assisted living is known, we all must be highly committed to consumer protection, and the key components of this commitment are disclosure, needs assessment, and service planning.

I have been asked to make assessment and service planning a focus of my particular testimony, and at this time, I would like to ask the Chairman's permission to submit a written statement from AAHSA which addresses the GAO report more broadly, and I believe you have that already.

The CHAIRMAN. That will be received, as I stated previously.

Mr. PAINTER. Thank you. From prior testimony, we have seen that the process of screening and assessing residents' needs and developing from that a service plan and updating it regularly is absolutely critical. Residents need to be assured that they will receive appropriate services appropriately. This process, whether it is called case management or care coordination, is the foundation of high quality, and both the resident and the family need to be involved if assisted living's overarching philosophy is to be realized. That is, that the resident's autonomy, independence, dignity, and choice are to be maximized and protected.

In our particular facility, Eaton Terrace II, which is Medicare certified and designed to serve the needs of low-and moderate-income elderly, the process begins with a thorough assessment of the resident's needs. Its purpose is to determine whether those needs can be met in our facility and to help us, in turn, ease the transition of the resident into his/her new home.

The assessment is linked with a physician review, contact with home health care professionals, discharge planners, and family members. The resident's family is invited to participate, but we also ask residents to speak for themselves, because ultimately that is who we are responsible to. If the resident's answers indicate some degree of dementia or error, more complete data can be obtained elsewhere without causing that individual discomfort or anxiety. If the assessment is favorable, the last question we usually ask is, "How do you feel about moving to Eaton Terrace?"

The assessment is the foundation of the service plan and the plan specifies what services are to be provided, in what amount, how often, and for how long. For example, a typical plan might specify that a resident needs help with bathing three times a week and that according to the resident's preference, the assistance shall be provided in the morning and shall consist only of help getting in and out of the shower.

At Eaton Terrace II, we use a case management team to develop and modify that service plan. This is usually modified to address a change in the resident's health status or behavior. Often, this results in a move to our congregate facility because of improved status. The resident does not need the level of service originally identified. At still other times, it results in a transfer to rehabilitative or skilled care when home health services are no longer sufficient or when the level of need moves beyond that which is permitted under our particular State's regulations.

We take a holistic approach, which says basically "we will help you take care of yourself," rather than the opposite philosophy of "we will take care of you." We work together as partners with the resident to maximize that individual's quality of life, which results in greater resident and family satisfaction.

At Eaton Terrace II, I want to stress that we found that medication monitoring, good nutrition, increased socialization and physical activity, and prompt response to changes in residents' status can reduce the number of emergency room visits and hospitalization.

You might also be aware of the Assisted Living Quality Coalition that has developed a quality initiative for the industry. This was

participated in by many of the groups represented here on this panel, as well as two consumer groups. The coalition's model State guidelines stress individual choice and the ability to age in place. Because of the emphasis on flexibility, the coalition views assessment, monitoring, and service coordination as essential. Mr. Chairman, we have also provided the committee a copy of that report, which we would like to have entered for the record.

Mr. Chairman and members of the committee, we urge you to recognize assisted living as a vital residential and services option for America's elderly. We also urge that you recognize that the present State regulatory environment allows innovation to flourish. Ultimately, this means more options for the consumer. But we also urge you to consider the consumer-oriented outcome-based approach to quality that the Assisted Living Quality Coalition has outlined in its consensus report.

During this discussion, we would also hope that you would look purposely at how long-term care is financed in this country. Our goal should be for everyone to have access to the supportive services and care that they need while remaining as independent as possible. This is not only cost effective, but improves quality of life. Assisted living, we believe, has an important continuing role to play in providing these opportunities. Thank you.

[The prepared statement of Mr. Painter follows:]



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STATEMENT OF
REVEREND DEAN PAINTER
President and CEO of the Eaton Terrace Group

BEFORE THE
SENATE SPECIAL COMMITTEE ON AGING
ON
THE GAO REPORT ON ASSISTED LIVING
APRIL 26, 1999

*Representing not-for-profit organizations dedicated to providing quality
health care, housing and services to the nation's elderly*

STEPHEN E. PROCTOR, CHAIR **LEN FISHMAN, PRESIDENT**
Field Offices in Albany • Chicago • Denver

INTRODUCTION

Good afternoon, Senator Grassley, Senator Breaux, and members of the committee. I am Reverend Dean Painter, President and CEO of the Eaton Terrace Group which owns and operates an assisted living residence and Section 8 congregate housing and independent living program for the elderly in Lakewood and Denver, Colorado. I serve on the board of the American Association of Homes and Services for the Aging (AAHSA) and as chair of the association's assisted living committee. On behalf of AAHSA's membership, I am pleased to present testimony that addresses quality and consumer protection issues in assisted living.

AAHSA is a national nonprofit organization representing more than 5,200 not-for-profit assisted living residences, continuing care retirement communities, senior housing facilities, nursing homes and community-based organizations that serve more than one million older persons daily. More than half of AAHSA's members are affiliated with religious organizations; the remaining members are sponsored by private foundations, fraternal organizations, government agencies, unions, and community groups. With strong community involvement and long-standing community ties, AAHSA and its members are deeply committed to providing quality care to the people we serve and to meeting the needs of these individuals in a manner that enhances their sense of self-worth and dignity, and that allows them to function at their highest possible levels of independence. For the past thirty-six years, AAHSA has been an advocate for the elderly and for a long-term care delivery system that assures all those in need of high quality services and quality of life.

Twenty-five percent of our members provide assisted living. Our members were providing assisted living long before the term became part of the long-term care vernacular. The roots of assisted living in the United States are found in the not-for-profit homes for the aging at the turn of the last century.

The GAO Report

The report of the General Accounting Office, which is the subject of this hearing, was requested to look at quality and consumer protection issues in assisted living.

The report is based on 622 survey responses from licensed assisted living communities nationwide and a review of consumer protection and quality of care issues in four states: California, Florida, Ohio, Oregon. The four state reviews included interviews with state licensing officials, ombudspersons, adult protective services staff and Medicaid fraud control units, if applicable, and an examination of reports of on-site surveys and inspections conducted by state licensing staff.

The GAO report affirms three basic, positive and widely-held beliefs about assisted living:

- 1) A wide variety of models exist which give consumers a desirable choice of settings;
- 2) State regulation is a workable approach for oversight; and
- 3) Consumer protection is the key to preserving both the flexibility and accountability of this service option.

Variety is Good. The GAO indicates that assisted living facilities exhibit a great degree of variety, which extends across states, within states and within local communities. Variety also exists in state regulatory requirements, services provided and type of physical structure.

The number and variety of options give consumers the choice they need in determining what is most appropriate to their circumstances. The varying needs of assisted living consumers necessitate a range of responses. The "typical" 82 year old woman residing in assisted living is a composite of many different people with a wide range of supportive and health related needs. The level of family support that may or may not supplement services differs. Financial needs may also vary.

State regulation works. GAO did not *discover* problems within assisted living. The GAO *disclosed* problems *already identified* by state agencies. Twenty-two states have licensing rules for assisted living. The remainder have regulations that govern assisted living, although the licensure category may be called by another name such as adult residential care. Although the GAO report did not address enforcement, we know from the report's account of state survey results that state agencies *are* inspecting assisted living facilities at the present time. Each year several states revisit their assisted living regulations. Sixteen states currently are studying or developing rules or have rules pending¹ for assisted living, which signifies to us that regulation is keeping pace with developments in the field.

A commitment to consumer protection is required. Maintaining the variety and flexibility for which assisted living is known requires a high level of commitment to consumer protection by providers. Disclosure and assessment and service planning are key concepts of that consumer protection.

Disclosure

A variety of options, the hallmark of assisted living, presents a challenge to both consumers and providers. The consumer must choose a facility based on sufficient, accurate information about an assisted living facility so he or she may make the appropriate decision regarding his or her living and service arrangement.

Providers have an obligation to present accurate, precise and understandable information to consumers about their programs, including but not limited to:

- a description of the guiding philosophy of the assisted living program;
- the criteria for admission, transfer and discharge;
- a description of services offered by the residence and the fees for those services;
- a description of services that the residence will arrange to be provided by another organization and the fees for those services;
- a list of services that residents or their caregivers may provide or arrange to have provided and any time limitation associated with provision;
- services not provided;
- circumstances under which a resident's need for services will be reviewed, and if necessary, revised; and
- a copy of the statement of resident rights.

Marketing materials must be straightforward in describing the assisted living community and should not offer conflicting statements of who can be served and for how long.

AAHSA is strong proponent of disclosure in assisted living. The Association's manual "Operational Practices for Assisted Living," includes a sample resident contract that providers might use in developing their own resident agreements. The Assisted Living Quality Coalition, which is described below, includes a detailed section on resident application, contracts and agreements within its model guidelines. We believe that quality is achieved through a partnership between providers, consumers and other stakeholders where all are given the tools they need to improve quality and make informed decisions.

Resident Assessment and Service Plans

The process of screening and assessing a resident's needs, and developing and regularly updating a resident service plan, is **absolutely critical** to assure that residents receive the services they want and need in an appropriate manner. This process, also known as case management or care coordination is the foundation of a high quality assisted living program. Resident and family involvement is the key to assuring that the philosophy of assisted living is attained -- that is, the resident's autonomy, independence, dignity, and choice is maximized and respected.

At my facility, Eaton Terrace II, the assessment process begins with a seventeen page document which has evolved over ten years experience in evaluating the needs of frail elders. The purpose of the assessment is to: 1) assess the individual's level of acuity and whether his or her needs "fit" with our service package; and 2) to help us in getting to know the person better and to assist us in making the pending move less threatening and more comfortable.

The assessment is linked with a physician review and contact with home health care professionals, discharge planners (where the resident has been hospitalized) and family members. The resident's family is invited to participate in the assessment process, but is instructed not to answer for the resident because it is important that we learn how the potential resident perceives his or her level of functioning. If the prospective resident's answers indicate some degree of dementia, more complete data can be obtained elsewhere without causing discomfort and anxiety for the resident. If the assessment is favorable towards move-in, the last question we usually ask is: "We would be pleased to have you as a resident, but how do you feel about making a move to Eaton Terrace?"

It also must be pointed out that because many assisted living residents receive home health care services through Medicare certified home health agencies, the residents will also be assessed by the home health agency.

The resident assessment plays a critical and essential role in developing, with the resident's input, the initial service plan for his or her stay with us. The plan specifies what services are to be provided, in what amount, how often and for how long. For example, a typical service plan might specify that a resident needs help with bathing three times a week and that according to the

resident's preference, the assistance shall be provided in the morning and shall consist only of help getting in and out of the tub.

The initial assessment is used as a baseline for evaluating a change in health status or behavior during occupancy. At Eaton Terrace II, we use a case management team to develop and modify the service plan to assure that it addresses the resident's current needs and preferences. The plan may be modified to address a resident's change in acuity and, at times, to determine whether the resident's needs exceed the ability of our program, staff and licensure requirements. In several instances, review of the resident's service plan resulted in a move to our congregate facility because of improved status. At other times, it has resulted in transfer to rehabilitative or skilled care when home health services were no longer sufficient to meet the individual's needs or safety.

The assessment and service plan development process fosters a holistic or "wellness" approach to care in which the resident is encouraged to function at a maximum level of independence. Further, because a wellness approach to assisted living says, "We will help you take care of yourself" rather than "we will take care of you," it requires a partnership between residents and providers that enables, encourages and expects residents to actively engage in all decisions about their lives. The resident has ownership and choice in the development of a service plan, enhancing his or her sense of self-worth and dignity. Residents and providers work together to maximize the resident's quality of life resulting in greater resident and family satisfaction.

Several years ago, when AAHSA was developing its "wellness model" of assisted living, it interviewed close to fifty assisted living providers across the country. They were in universal agreement over the importance of incorporating an assessment and service planning process into assisted living operations. AAHSA's wellness model that's outlined in our "Operational Practices for Assisted Living" includes an aggressive case management strategy that assures early detection of potential problems and timely intervention to avoid an acute care episode. At Eaton Terrace II, we have found that medication monitoring, good nutrition, increased socialization and physical activity, and prompt response to changes in resident status can reduce the number of emergency room visits, hospital days, and utilization of the acute care system.

The GAO study found that state regulation and provider practice varies in how assessment and service planning should be or is conducted. According to "State Assisted Living Policy: 1998" prepared by the National Academy for State Health Policy, all but two states require providers to conduct a resident assessment and most all those require that it be conducted prior to move-in. Of the two that don't specify resident assessment as a requirement, one (Colorado) requires that a service plan be developed. The point is that while the method may vary, states are requiring and providers are conducting resident assessments and service plans to assure that the provider is capable of meeting the resident's needs and has a conscious plan for doing so.

Making a Good System Better

Many of you are aware of the Assisted Living Quality Coalition, a group of six national consumer and provider organizations that began working together over three years ago to develop a new approach for achieving quality in assisted living. The Coalition consists of

AAHSA, AARP, the Alzheimer's Association, the American Seniors Housing Association, the Assisted Living Federation of America and the National Center for Assisted Living of the American Health Care Association. The Coalition developed a quality initiative for the industry through the input of countless stakeholders.

The initiative is outlined in the Coalition's 1998 consensus report, *Assisted Living Quality Initiative: Building a Structure that Promotes Quality*. The report presents an overall framework for a quality improvement system and includes many recommendations. The report includes model guidelines that states might use in the development of state standards. The guidelines provide a definition of assisted living, and describe the philosophy, services, environment, and consumer protections that should be required of assisted living providers.

The Assisted Living Quality Coalition's model state guidelines stress individual choice and the ability to age in place. As a consequence, much specificity that is usually included in standards for long-term care setting is left to negotiation between residents and providers in the service plan. Because of this emphasis, the coalition views assessment, monitoring and service coordination as essential and provides some detail on how service plans should be developed, negotiated and updated in their guidelines. Mr. Chairman, I have a copy of the Coalition's report that I'd like to submit for the record.

Throughout development of its initiative, the Coalition focuses on the goal of providing the highest quality of life possible for those living in assisted living settings. Paramount was the concern that the needs and preferences of the consumer remain at the center of the delivery of assisted living as the industry grows and matures. The Coalition believes that the core of any effort to preserve the assisted living model in the future must focus on ensuring that providers retain needed flexibility in providing assisted living services. Further, the Coalition believes that quality improvement efforts must focus on key outcome measures. It is Coalition's hope that the initiative will offer a new way for consumers, providers, government and third party payers to work together to foster a system that responds to the unique needs of each resident.

The Coalition currently is preparing to study the feasibility of establishing an independent National Assisted Living Quality Organization proposed in our initiative. This would be central to developing the needed information sources and managing the quality improvement system we envision. The Coalition is also holding an Assisted Living Outcome Measures Summit in June 1999, to obtain and share the most current information on the status of outcome measures.

CONCLUDING REMARKS

Mr. Chairman and members of the committee, we urge you to recognize the importance of assisted living as a residential and services option for America's elderly. We urge you to recognize that the present state regulatory environment allows innovation and creativity to flourish, which ultimately gives the consumer more options from which to choose. We believe that this environment must continue. We urge you to consider the consumer-centered, outcome based approach to quality outlined in the Assisted Living Quality Coalition's initiative.

In the future we need to look at how long-term care is financed in this country, so that everyone has access to the supportive services and care they need, while remaining as independent as possible. Assisted living has and will play an important role in providing these opportunities.

We thank you for this opportunity to share our views.

¹ National Academy for State Health Policy, "State Assisted Living Policy: 1998"

The CHAIRMAN. Thank you, Reverend Painter.
Mr. Lasky.

STATEMENT OF WILLIAM F. LASKY, PRESIDENT AND CHIEF EXECUTIVE OFFICER, ALTERNATIVE LIVING SERVICES, BROOKFIELD, WI, ON BEHALF OF THE ASSISTED LIVING FEDERATION OF AMERICA

Mr. LASKY. Thank you, Mr. Chairman and committee members, for giving me this opportunity. I am presently the President and CEO of Alternative Living Services. We are the nation's largest provider of assisted living, operating 369 facilities coast to coast. I am also the past Chairman of the Assisted Living Federation of America, the largest trade association representing our industry.

I founded this company in the early 1980s with one small home to provide an alternative to institutionalization, and over the last 18 years, I have personally seen impact on the lives of thousands of Americans, residents, and families who have really been the fuel behind the assisted living movement.

I commend you as a committee for reviewing this industry, now a \$13 billion long-term care platform in our nation. This industry is unique for health care. It was created like other industries in our society, by listening to customers, responding to customers, or adult children and their seniors.

Variety, innovation, and market forces have been successfully integrated into this health care movement. We have welcomed long-term care back into the U.S. economy. All of us today find it refreshing to attend this hearing, especially with the title having words like "customer" and "shopping". We have come a long way with long-term care in our nation with a title like that.

Now for my mission of why I am here. I have been asked specifically to comment on aging in place. We have seen a societal shift and a push-down of care out of our conventional long-term care health care system and assisted living has filled that gap.

I can best describe aging in place by talking about Nell. Nell is a 102-year-old resident who lived in a nursing home. She wanted to move into an assisted living residence and she did it on her own steam, arranged her own transportation, and told her daughter to meet her there. At the age of 104, the State of Kansas wanted to move Nell back into a nursing home. Nell needed assistance with transferring out of the wheelchair and assistance with eating. Her family, her friends, and enhanced staffing patterns allowed Nell to stay at that assisted living residence in Kansas for three more years. Nell passed away in January at the age of 107. Nell still had the ability to make her choice.

As you can hear and as you have heard in this hearing, there are artificial glass ceilings State by State on what is acceptable health care acuity. It has been a habit in our nation for the past 20 years, when you need more care, you need institutional care. The same care you get in your home, you should be able to receive in an assisted living residence, your new chosen home. When we discuss consumer protection, let us make sure we protect consumers from having a third party mandate a move. You can set up an ICU unit in your home. Health care is portable. But because Nell needed some more assistance, she risked a mandated move.

In the GAO report, there are examples of inadequate care. We have heard from the family members that took out their time to share that with us today. We recognize we have problems. We recognize we have challenges. We are here to work with you.

Assisted living is not a free-for-all for health care. We are regulated and licensed State by State. Inspections are routinely made. Detailed regulations do exist in some of the States we have talked about today. State officials today already have the authority to mandate compliance and to take enforcement actions. Regulations do exist. They are diverse State by State, but quality of care, safety, and the sanctity of our vulnerable population is watched over today.

We are not an industry that is regulation-averse. We want to be regulated by outcome of care, not by recipe, not by prescriptive formulas. We have learned as a society that we cannot regulate quality of life.

I would like to conclude by talking about one sacred right, and I brought a prop with me today and that is this business card. That sanctity that we want to preserve is the right to choose where we live.

This is Elroy's business card. Elroy is an 88-year-old retired grocer who lives in one of our residences. He chose to live there. He is so proud of where he lives, he had this card made. We want to in this hearing as we navigate through these issues continue to focus on Elroy's ability to not only choose but to rechoose in the State where he lives.

As we focus on quality and consumer rights, we need to preserve the success ingredients of why we have a new long-term care platform today, competition and customer power. We get surveyed for quality every day by our customers. I want to thank this committee for the work you are doing for our nation's seniors.

[The prepared statement of Mr. Lasky follows:]



**STATEMENT OF
WILLIAM F. LASKY
CEO, ALTERNATIVE LIVING SERVICES**

**FOR THE
ASSISTED LIVING FEDERATION OF AMERICA**

**BEFORE THE
UNITED STATES SENATE
SPECIAL COMMITTEE ON AGING**

**on the GAO Report "Shopping for Assisted Living: What
Consumers Need to Make the Best Buy"**

April 26, 1999

Good afternoon, Mr. Chairman and members of the Committee. I am William F. Lasky, President and Chief Executive Officer of Alternative Living Services (ALS) - the nation's largest operator of assisted living residences for the elderly. We currently operate 369 residences nationwide serving almost 16,000 residents in 25 states. ALS is also the country's largest operator of freestanding Alzheimer's care residences.

Founded in 1981, ALS is one of the pioneering companies in what is now referred to as the assisted living industry. ALS' national presence and my work as the immediate past Chairman of the Assisted Living Federation of America (ALFA) has allowed me to actively participate in the unprecedented growth and development of this industry. Today, in every state, seniors are afforded opportunities to enjoy life in assisted living residences.

On behalf of ALFA, I want to thank you for the opportunity to address the Committee and respond to the General Accounting Office (GAO) Report on assisted living.

ALFA is the only national trade association devoted exclusively to the assisted living industry and the population it serves. ALFA's 6,000-plus members include for-profit and non-profit, large and small assisted living providers. ALFA members operate freestanding assisted living, continuing care retirement communities, and other entities that may have an assisted living wing, such as hospital systems, nursing homes or independent living residences. ALFA has 31 state affiliates covering 34 states to work with regulators and legislators on the state level. ALFA's primary mission is to promote the interest of the assisted living industry as well as enhance the quality of life for the residents and family members it serves. In keeping with that goal, ALFA has worked to educate providers and consumers to ensure that customer satisfaction, quality of life and quality of care are paramount in assisted living.

The findings of the GAO report which are the subject of this hearing address the issues of quality of care and consumer protection in the assisted living industry. The report's findings are based on data gathered from survey responses and interviews with assisted living providers, residents and family members, and state regulators in California, Oregon,

Ohio, and Florida. Since we were permitted only a brief review of the GAO's findings prior to today's hearing, we respectfully request the opportunity to add to our written testimony after we have had a chance to more completely study and evaluate the report.

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

Definition of Assisted Living

Assisted living, as defined by ALFA, is a combination of housing, healthcare and supportive services designed to respond to the individual needs of those who require help with activities of daily living but not necessarily the round-the-clock skilled medical care provided in other long-term care settings. Trained staff members are available 24-hours-a-day to allow residents to age in place and receive the support and assistance they require to meet their changing healthcare and personal needs. The typical assisted living resident is a single or widowed woman in her eighties who on average needs help with three activities of daily living, such as bathing, dressing or taking medications.

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

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

- Cost-effective quality care personalized for the individual's needs

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

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

Industry History

We are a young, dynamic industry that continues to evolve. In the 1980's, a new generation of caregiving settings dedicated to a residential, home-like environment came into being in response to consumers' wishes for alternatives to traditional long-term care settings. These early customers were willing to forego existing entitlement programs in institutional settings by paying out of their personal funds so that they or their loved one could enjoy a more residential, home-like environment. In other words, they were willing to share the responsibility associated with this new, more flexible model to preserve their independence for as long as possible. As a result, consumer desire to find a non-institutional option has shaped the design and service delivery in assisted living residences in every state.

Since then, the industry has evolved from a cottage industry to an estimated \$13 billion industry that is working to meet the care needs of consumers who want greater choice and more alternatives to long-term care. Driven by market forces and customer demand, the assisted living movement has become the option of choice for many seniors nationwide.

Increased competition has further empowered customers to choose from a variety of providers and find the setting that best meets their own personal needs or preferences.

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

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

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

Aging in Place: A Definition

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

Healthcare is Portable

In the past, and even now, generations of older adults have remained in their homes until the end of their lives supported and aided by family, friends and neighbors. With advances in healthcare technology and community-based service options, such as home healthcare and hospice, many frail or ailing older Americans are able to remain at home for the rest of their lives rather than receive care in an institutional setting such as a hospital or nursing home. This “portability” of healthcare services, coupled with the philosophy of aging in place, has led to assisted living residences becoming a place where a resident can spend the last years, months, or weeks of their life surrounded by family members, friends, caring staff members and community health care professionals. As a result, residents and their families around the country have come to regard their community of neighbors and care providers in assisted living residences as their home, and long to remain at that home for the rest of their lives.

Customer Choice

Under the aging in place philosophy, residents and family members can make choices and are involved in the process of organizing their care. The choices consumers sometimes

make can be risky for a provider. We as providers engage in a balancing act between what an individual consumer wants and what is safest for them. If a resident were prone to falling and that person were restrained, it would clearly prevent a fall. But it also would greatly diminish the resident's quality of life and level of control. Our residents and their family members recognize and embrace our willingness to share the risks inherent in living in a residential environment. Our responsibility as providers is to clearly communicate which services will be provided by the residence staff, and what services the resident may need or desire to contract from the community.

A Positive Environment for Residents with Alzheimer's Disease

Assisted living residences have come to be recognized as appropriate and desirable environments for individuals with Alzheimer's disease and other forms of cognitive impairment to live and age in place. This notion is supported by the National Alzheimer's Association and addressed in their publication Residential Settings which offers guidelines and recommendations for providing care in assisted living residences. People affected by Alzheimer's disease typically do not have a great need for medical treatment and intervention. Rather, many are in good physical health but need a secure, supportive environment with 24-hour assistance and supervision – a high touch/low tech setting in which to live and flourish. At one time, the diagnosis of Alzheimer's disease translated into a life destined to end in a nursing home setting. Today, residents with Alzheimer's disease are able to live in supportive residential environments which focus on helping them and their families cope with the signs and symptoms of their progressive cognitive decline. Their ability to remain in a familiar, caring environment is vital to improving their daily lives and ability to function.

In response to customer demand for more home-like yet supportive settings for individuals with dementia, assisted living operators have developed many innovations for this special resident population. These include "memory" boxes outside of residents' units, special wayfinding systems throughout the residence, and walking paths through meaningful "life skills" rooms – such as an office, a tool shed, a woodworking area and user-friendly

kitchens – that allow residents to participate in everyday experiences that were once important and enjoyable to them.

Assessing and Monitoring Residents' Changing Needs

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

Assisted living caregivers are responsible for monitoring, observing and communicating the residents' needs. By listening and observing, staff members can share their daily assessments with the resident's doctors, family, pharmacist or other healthcare professional involved in the resident's care. Most importantly, the resident and family members are empowered to become an active part of any problem-solving that may be required. Together, residents, family and the staff determine what services should be provided by the staff to meet the resident's changing needs. In some instances, a decision may be made that the resident's needs can be better met by bringing in community resources, such as hospice, to allow the individual to age in place. When a hospitalization is required, staff frequently coordinate with the family and the resident to provide or bring in the appropriate resources to facilitate the transition once the individual returns to the assisted living

residence. Physical therapy, occupational therapy or other services can be provided to help the resident regain functional abilities. Adapting staffing patterns, accessing home health services, or creating a specialized care program are decisions made as a team. This caring partnership allows residents to continue to navigate their own destiny as much as possible.

Barriers to Aging in Place

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

In states that do not allow aging in place, the resident typically must be discharged to a higher level care setting when they no longer meet the state's retention criteria. Depending on the state, a resident might be discharged when they become incontinent, require assistance with transferring or walking, require assistance with more than the allotted number of activities of daily living, or need more than the allotted number of hours of nursing care in a week. There are even a few states that believe residents with Alzheimer's disease, regardless of their physical capabilities, must be placed in a nursing home and should not have the option of living in an assisted living residence.

Since health care is portable, many consumers believe that they should be entitled to receive the same level of health care within an assisted living residence as they would in a private home. The assisted living industry agrees with this perspective. State regulators should not require that residents be moved from their own home to a nursing home when

their needs change. Yet that is the case if their home happens to be a supportive community environment like assisted living. Consumers are beginning to recognize that they have the right to choose where they live, irrespective of their age or physical condition. The Fair Housing Amendment Act of 1988 and the Americans with Disabilities Act of 1991 give civil rights backing to the demand that supportive services be provided to persons with disabilities of any age in living arrangements they may choose.

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

ALFA advocates partnering with states to develop a variety of affordable options for reimbursement to maximize consumer choice. We are considering a variety of options including consumer care accounts, a voucher program, a Medicare Partnership Plan and an Individual Long Term Care Block Grant. We believe that any such system should allow portable funding for the consumer.

Consumer Protection

There is an erroneous perception that there is a lack of mechanisms to address quality issues and consumer protection. Assisted living providers are surveyed, or inspected, in almost every state prior to opening a residence and annually thereafter. Most states also have a mechanism where surveyors will visit the residence if a complaint is lodged with the state agency. The survey process itself varies from state-to-state ranging from a day visit with a surveyor to a three to four day inspection with three to four surveyors. Typically,

the surveyor produces a written report of inspection that is available to the general public, residents, families and potential consumers. The surveyors can cite deficiencies, require plans to correct cited deficiencies and take enforcement action.

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

Ensuring Quality of Care

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

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

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

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

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

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

To date, the ALQC has produced an overall framework for implementing the initiative, including guidelines to states on establishing minimum standards, which are the result of the Coalition's research, brainstorming, numerous input forums and, most importantly, compromise. These guidelines are meant to provide guidance to state legislators and agencies for finessing their own regulations and quality initiatives and are not intended as strict "standards of care." The guidelines are meant to evolve over time and should be viewed within the parameters of existing progressive and innovative state programs. ALFA is pleased that the Coalition was able to bring about consensus on the basic issues

for this industry such as definition, philosophy and the need to develop quality indicators to measure actual quality outcomes and resident satisfaction.

Industry Consumer Education Efforts

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

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

◆ Consumer Awareness and Protection

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

◆ Staff Training

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

◆ Transitioning to an Assisted Living Residence

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

their experiences and challenges as they moved through this decision-making process to make the transition into assisted living.

◆ **Sharing Risk**

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

◆ **Resident and Family Satisfaction**

Resident and family satisfaction surveys are an important tool in measuring quality. Many assisted living operators have developed their own forms and routinely collect this information. In an effort to gauge industry benchmarks nationwide, ALFA also has developed a uniform survey tool called the National Resident Satisfaction Survey, which has been distributed to 30,000 residents, staff and family members to date.* After responses are collected and analyzed, individual assisted living residences will be able to evaluate their performance and the relative importance of each area as reported by residents, families, and employees.

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

◆ **Resident Agreements and Disclosure Forms**

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

Conclusion

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

Above all, assisted living must remain:

■ **Responsive to consumer choice and market forces.** The popularity of assisted living as a model has been in the willingness of providers to share the responsibility and, yes, even the risk associated with helping a frail older person who above all wishes to navigate their own destiny without anyone telling them how to do it. We believe the best way to accomplish this is to allow the market to be driven by the consumer.

■ **Residential rather than medical or institutional,** granting an assisted living resident all the same rights to age in place that they would enjoy if living in their own individual home. The desire to control one's living environment, to choose where and how to live, is a very personal matter for Americans. This desire does not simply end when a person turns 82 or requires help with their daily needs.

■ **Philosophy-driven.** The industry believes the most progressive provider policies and state regulations are those which hold basic health and safety concerns to be paramount, but also quality of life and the importance of consumer choice. This goes back to our philosophy of preserving a resident's independence, privacy, dignity and spirit.

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

Mr. Chairman, I wish to thank you for the opportunity to appear before the committee today and would be pleased to answer your questions.

THE ASSISTED LIVING FEDERATION OF AMERICA (ALFA) ETHICS/MISSION STATEMENT

A LFA members are dedicated to providing excellent care that meets their residents' needs in an ethical and responsible manner. To this end, ALFA members have adopted the following general statement of principles to guide their actions. While recognizing that the needs of seniors are unique and that no uniform "standard of care" can be developed which embraces or addresses the needs of all residents, ALFA members believe these general principles provide a basic framework of our mission to the communities we serve and our entire society.

TO OUR RESIDENTS AND THEIR FAMILIES WE PLEDGE:

TO ENHANCE THE LIVES OF OUR RESIDENTS...

- Encourage residents to achieve and maintain their maximum level of independent function.
- Provide choices and options, through risk management programs and other means, to meet resident's needs and encourage them to continue to be actively involved in decisions about their care.
- Preserve each resident's dignity and privacy.

TO NURTURE OUR RESIDENTS...

- Assess each resident's needs and reassess appropriately.
- Provide appropriate and cost-effective services.

TO PROVIDE SAFE ENVIRONMENTS AND CARING, COMPETENT STAFF...

- Ensure staff have appropriate background, skills, experience and ensure that they receive necessary training to support the services offered.

TO INFORM RESIDENTS AND FAMILIES ABOUT SERVICES PROVIDED...

- Detail services available, related costs and policies relating to charges, including any changes in charges.
- Explain thoroughly the criteria or parameters for changing the level of service, including policies relating to transfers from the residence.
- Where appropriate, provide family members access to all of the information about services and involve them in decision making.
- Identify other services available through arrangements with the provider or independently.
- Disclose existence of financial relationships with affiliated or independent providers of ancillary services.

TO OUR COMMUNITY WE PLEDGE:

- To coordinate care with other providers when necessary.
- To help the public and policymakers understand assisted living.
- To maintain a responsive attitude to evolving care needs of residents and respond proactively and cooperatively with other groups to best serve the needs of residents.



The CHAIRMAN. Mr. Lasky, thank you, Mr. Lohr.

STATEMENT OF ROBERT LOHR, PRESIDENT, PERIDOT ENTERPRISES, PITTSBURGH, PA, ON BEHALF OF THE NATIONAL CENTER FOR ASSISTED LIVING

Mr. LOHR. Good afternoon, Chairman Grassley and members of the committee. I am the founder of Peridot Enterprises. I am a nursing home administrator. We own a nursing facility in Pennsylvania. We own and operate five assisted living facilities in Florida; and, as of last week, I am the chairman and CEO of a small public company that owns and operates eight assisted living facilities in Florida. Over the years, I have been involved in opening more than 30 assisted living facilities and operating them.

I am here on behalf of the National Center for Assisted Living, "NCAL", the voice of assisted living in the American Health Care Association. We represent approximately 2,000 assisted living and residential care facilities across the nation. I have been asked to compare nursing and assisted living facilities as they relate to the various topics we are discussing today.

Assisted living is in its adolescence in this country. It is a viable alternative for many to a nursing facility. Our challenge, our mutual challenge, is not to allow what we have done to the nursing home industry to happen to this refreshing consumer-driven business. It is essential that governmental policies should nurture and not stunt growth. We know the many problems and conflicts related to the Federal and State regulation of nursing facilities. It would be a grave mistake to burden assisted living with a similar system.

Assisted living focuses on the individual resident, maximizing choice and fostering independence. Our customers have told us that this is what they want and they are driving the growth, not reimbursement, not certificates of need, not Federal programs, and not regulations.

Since 1978, I have seen the entrepreneurial spirit of my nursing home colleagues beaten time and time again, not by customers and referrers but by the constant pounding and pressures of reimbursement and regulation. In nursing facilities across the country, we have witnessed an adversarial survey process where the penalty for canceling a painting activity is the same as the one for a medication error. At virtually all costs, let us commit to mutually avoiding that path, which is laden with too many problems that we have created for ourselves and the residents and the citizens that we serve.

Assisted living has not been regulated to the same degree yet. Certainly there are fundamental desired conformities, for example, fire safety codes. Let us put them in place and then listen to the consumer. One-size-fits-all does not work. We want what our residents want, and that is individuality and independence.

The grievance processes in place for both nursing home and assisted living facilities are similar in many respects. In Florida and Pennsylvania, all residents are required to receive a written bill of rights on admission. It includes how to lodge a complaint within the facility and how to contact an advocate, an ombudsman, in the

community. Nursing facility requirements are almost identical in both states.

Assisted living and nursing facilities are required to assist residents in organizing and operating resident advisory councils. NCAL and all assisted living providers support the concept of self-governing resident councils.

Ombudsman programs, usually funded by government dollars, are available in most States for residents in both nursing and assisted living facilities. Training is important, due to the differences in wants and needs of residents in each of the two classifications.

Where do we go from here? Please remember my earlier pleading. Let us not repeat what we have done to the nursing home industry.

You are already familiar with the Assisted Living Quality Initiative released last August by the Assisted Living Quality Coalition. The initiative includes guidelines to assist policy makers, State policy makers, with their correct oversight of assisted living. It also includes initiatives that show a vision of a quality measurement system that focuses on customer-satisfaction and actual outcomes. Such quality measurement tools could be used by providers, consumers, and government to ensure that quality services are being provided and improved on a continuing basis.

Measuring quality should be ongoing. It is far better than an annual snapshot inspection. Continuous monitoring of certain "lighthouse" data is more current and reliable. It is also an excellent way to evaluate how well staffs are doing their jobs. Finally, it is an excellent method of assembling data which could be used in the development of facility report cards. Why not provide prospective residents and their family members with solid comparative data which will allow them to make a best decision based on their individual wants and needs?

NCAL has already completed a great amount of research in the area of customer satisfaction, and this research could be one of the building blocks for this consumer or facility report card. In June of this year, the coalition is meeting to start work on the development of performance indicators for assisted living.

We also need to think outside the box when considering the role of States in ensuring quality. We need to think beyond the role of traditional enforcer. Surveyors' initial roles should be those of advisors and consultants. Our common goal should be quality care through appropriate services that generate desired customer outcomes.

Creating a culture and a structure which will allow the regulator and provider to work together to achieve common goals is a far better model than that which is being employed today in other long-term care venues. Such an accountable partnership may be a dramatic difference, but the opportunity is there now. Commitment would help to carry the day.

Finally, long-term care, more than ever before, is better equipped to better serve our residents. Our residents should be the beneficiaries of the gains. Our greatest generation deserves the best, not our bickering, negotiating, and posturing for power. If we really believe we should listen to what the consumer wants, then let us commit to doing the right thing so residents may age in the right

place. Please let me repeat that, so residents may age in the right place.

We can work together to avoid the errors of the past and to allow assisted living to meet the needs of our residents and their families. Thank you very much.

[The prepared statement of Mr. Lohr follows:]

**TESTIMONY OF
ROBERT LOHR**

**ON BEHALF OF
THE NATIONAL CENTER
FOR ASSISTED LIVING**

**SENATE SPECIAL COMMITTEE
ON AGING**

APRIL 26, 1999

Good afternoon Chairman Grassley and members of the Committee. My name is Robert Lohr and I am Founder and President of Peridot Enterprises, Inc., which operates several assisted living facilities in Florida and a nursing and assisted living facility in Pennsylvania. I also have just recently become the Chairman & CEO of a small public company that specializes in assisted living in Florida. I have worked in the long term care industry for more than 20 years, starting my career in nursing homes and later diversifying into assisted living. During that time, I have developed, constructed or managed more than 25 assisted living facilities.

I am here today on behalf of the National Center for Assisted Living (NCAL), the assisted living voice of the American Health Care Association. NCAL represents nearly 2,000 proprietary and non-proprietary assisted living and residential care facilities nationwide. NCAL is committed to fostering growth in assisted living and ensuring that people have access to quality assisted living services by supporting responsible public policies, providing professional education and development services, and by being an information and research resource for the public, state and federal policymakers and the media.

Assisted Living: An Innovative Approach

Based on a Scandinavian model for senior living, assisted living first emerged in America during the mid-1980s, and that is when I first became involved in this exciting new industry. Unlike other medical models found in most health care settings, assisted living is based on a social model of care which translates into a holistic approach toward serving residents. Independence, autonomy and choice are words that define assisted living and are the concepts that have made assisted living so popular with the public. People living in assisted living residences receive help with their daily lives so that they can retain their sense of individuality and belonging in their communities. I have attached a more comprehensive summary of assisted living to my testimony.

State governments regulate the assisted living industry primarily through licensure and certification laws. Assisted living and residential care regulations vary widely across the nation but generally cover issues such as the physical setting, services, staffing, staff training, and resident admission criteria. Some states have very strict guidelines on who may live in an assisted living facility, while other states are more flexible and allow residents to "age in the right place" for longer periods of time. You heard from experts earlier this afternoon about how assisted living is being regulated. Instead, I want to speak to how and why governments should regulate assisted living differently than it has regulated the nursing home industry.

While there are many variations in the way states regulate assisted living, the greater freedom states have to design their own systems makes for more responsive and proactive oversight. We know too well the many problems and conflicts in the federal and state regulation of nursing homes. It would be a mistake to burden assisted living with a system that doesn't work. Alternatively, the focus on the individual is the

foundation of the assisted living philosophy. Indeed, it is consumers who have been driving the popularity of and growth in assisted living, not government programs, regulations or funding. This is an important fact to recognize.

Nursing facilities are required to follow myriad regulations from a multitude of state and federal regulatory agencies. It's a cookie cutter approach that's rooted in treating every resident and facility in a similar manner through regimented policies and procedures. This approach doesn't necessarily translate into the types of services and programs sought by residents and families. In the last 20 years I observed the nursing home industry shift from being relatively home-like facilities to routine-laden institutional settings in an effort to comply with regulation after regulation.

On the other hand, one of assisted living's greatest strengths is its ability to mold and shape itself to fit the needs of the individual customer: the forces shaping assisted living have come from the customer. Regulations, by their very nature, create a cumbersome system in a bureaucratic attempt to achieve conformity and maintain the status quo. In some instances, such as fire safety codes, regulatory conformity is desired and essential. However, in an industry that's designed to allow people to live as independently as possible, the way they would live their lives in their own homes, it becomes apparent that a "one size fits all" approach to regulating such an industry becomes difficult, if not impossible and certainly not desired by the consumer. Overly rigid regulation and inconsistent quality measurement will destroy individuality – the hallmark of assisted living.

Complaint and Corrective Action Process

I was asked to discuss how the grievance and corrective process compares in both the nursing home and assisted living industries. The assisted living and nursing home industry's complaint and corrective action processes resemble one another to a degree. While they are similar in structure and both industries have systems to effectively handle and resolve resident complaints, the assisted living industry has the flexibility to work cooperatively with states.

For example, in Pennsylvania and Florida, the law requires assisted living facilities to give residents a written bill of rights upon admission. The bill of rights must advise residents how to lodge a complaint within a facility and mandates that assisted living facilities post the name, address, and telephone numbers of the district ombudsman and other adult advocacy organizations. Similarly, nursing facility regulations spell out a resident's right to voice grievances and the facility's duty to actively seek a resolution. NCAL believes that all facilities should have clear policies and procedures for resolving complaints from residents or their families.

If complaints cannot be resolved internally, residents can also turn to state ombudsman programs for resolution. The ombudsman program works the same for assisted living facilities as it does for nursing facilities. Because the same ombudsman is

frequently used for both settings, NCAL believes that it is important to train ombudsmen about assisted living to ensure that they understand the differences between the two settings and don't perform their duties based solely on their experience with nursing facilities.

Finally, just as nursing facilities allow residents to organize and participate in resident groups that respond to resident grievances, assisted living facilities in Pennsylvania and Florida are required to facilitate the organization of resident councils, through which residents may lodge complaints. NCAL strongly supports the concept of self-governing resident councils and has included this in our list of resident rights that are paramount to the assisted living consumer.

As a young and expanding industry, assisted living has been able to utilize the best practices found in long term care and tailor them to meet the needs of residents.

Government Oversight in the Next Century

You already are familiar with the Assisted Living Quality Initiative released last year by the Assisted Living Quality Coalition (ALQC), a group comprised of NCAL, the other three organizations represented on this panel, the Alzheimer's Association and AARP. The initiative includes guidelines to assist state policymakers with their own oversight of assisted living.

It is NCAL's and the ALQC's strong belief that assisted living regulation and oversight should remain on the state level. More importantly, the ALQC initiative envisions a quality measurement system for assisted living that focuses on customer satisfaction and actual outcomes. Such a system could be utilized by providers, consumers and government to ensure that quality services and care are being maintained and, even more importantly, improved on a continuing basis. Developing a quality performance measurement system would better serve the interests of the assisted living customer by providing each resident with powerful input into the quality evaluation process and the delivery of services. Let me highlight the direction in which we need to move.

Customer Satisfaction

Customer satisfaction is probably the single most important component of a quality measurement program. It's important for consumers, families and providers. It should be equally important to government. Assisted living is a people business with a holistic approach to care. Our main goal is not to cure a disease or illness as other health care providers do, but to help an individual manage and live life to its greatest potential. Tracking whether a facility is successfully achieving that goal in the minds of residents and families is paramount in assessing how well a facility is performing.

NCAL already has accomplished much in the area of customer satisfaction measurement in the assisted living setting. In 1996, NCAL, working with the Gallup Organization and the University of Wisconsin, conducted research and developed and tested a customer satisfaction assessment questionnaire. We would like to submit a copy of this questionnaire for the hearing record.

As part of our research and questionnaire development, we learned a great deal about what satisfies assisted living customers. Our research identified many key satisfiers in several areas such as management, resident's rights, facility structure, staffing, and assistance with transition upon moving into a residence. From our research we built a questionnaire designed to measure those factors that residents deem important to the sense of satisfaction and well being. Thousands of copies of that instrument have been distributed free of charge and are being used by assisted living facilities nationwide. This is the type of instrument that the ALQC envisions being used by providers to measure customer satisfaction.

Performance Indicators

Beyond customer satisfaction, any quality measurement system must also include measurement of actual performance. The ALQC identified three primary outcome measures: clinical, quality of life and functional outcomes.

To be able to measure performance, certain data about each resident must be obtained, tracked and updated. From this data, quality indicators can be identified and utilized to track the outcomes of the care and services being provided by a facility. The benefit to such an approach from a facility operations standpoint is that problems can be quickly identified and fixed. NCAL strongly believes that quality measurement is an ongoing process, not an annual inspection. More importantly, a facility can use this data as part of its continuous quality improvement program. This data gives facilities the ability to measure their performance over a period of time and identify trends on a facility and individual basis. Facility data can also be included in a network of data from facilities across the country which would facilities to see how their performance compares to other facilities in their community, state, or nationwide. Continuous monitoring of performance is also a more dignified and reliable way for staff to evaluate how well they are doing their jobs.

Development of Assisted Living Performance Indicators

The ALQC is working to develop appropriate outcome performance indicators for assisted living. In June, the ALQC is holding a summit of stakeholders including regulators, providers, consumers and third party payers to hear from leading researchers on performance measures. Some of those researchers testified before you today. The ALQC's plan is to use the summit as the first step toward developing performance indicators. We don't have all the answers today about what those performance indicators will be and how they will be implemented. However, the ALQC, and NCAL in

particular, is committed to developing the indicators, testing them, and helping states and facilities utilize the indicators to measure performance outcomes.

State Monitoring of Quality

Performance outcome indicators and customer satisfaction data have been proven to be powerful tools in assuring quality in nursing facilities. NCAL believes the same will be true for assisted living residences. But they also have tremendous potential at the state level for monitoring quality. NCAL believes that states should use these measures in lieu of traditional survey processes for most providers. Rather than focusing on annual checklist inspections, states would be able to attain regular reports about a facility's performance throughout the year. Further, the information that they would use to evaluate facilities will shed far more light on how a facility is performing than any state survey could hope to deliver.

NCAL and the ALQC believe in the concept of separating the state's monitoring role into two distinct functions. The first role is one of consultant, the second as advisor. As consultant, the state would oversee the performance of facilities by monitoring outcome indicators and customer satisfaction data. When performance data indicate that a problem exists or may be developing, the state can work in a consulting role with the facility to precisely identify that problem and formulate a solution. The state's role as advisor would be to review facility plans to correct a problem and to make recommendations or share best practices and protocols with facility staff.

The common goal of both provider and regulator should be quality care and services. We believe creating a structure that allows both regulator and provider to work together to achieve this common goal will help ensure consistent quality and benefit the assisted living resident. States should also explore incentives for their best performers to recognize excellence in the assisted living field.

The partnership proposed by the ALQC is a dramatic departure from the way government regulates nursing homes. The nursing home survey and enforcement system is built on penalizing facilities for what they are doing wrong, regardless of the severity of the citation. It's a punitive system. A far more effective and efficient system is one where providers and regulators look at facilities' performance data on an ongoing basis. Providers should be able to ask the state for advice if it identifies a problem without fear of retaliation. Further, the state should be permitted to give that advice.

Clearly, the state has a duty and responsibility to ensure the well-being of residents living in state licensed facilities. Instances will occur when the state needs to ensure that a facility is living up to its responsibility to provide quality services. However, state regulatory staff responsible for enforcement should not be the same staff with advisory and monitoring responsibilities. It is important to avoid the commingling of these responsibilities if these two necessary functions are to operate in the manner in which each is intended. Despite these separate responsibilities, clear and open lines of

communication are necessary if such a two-tiered system is to work efficiently and effectively.

Other Uses of Performance Measures

Another compelling reason to utilize outcome indicators and customer satisfaction for assisted living is for third party payers that will utilize assisted living services. Managed care is likely to rely more heavily on assisted living in the future. Long term care insurance is another payer with a vested interest in facility outcomes. It is logical to build a system that measures performance in terms that these payers can use. It continues to be very unlikely that any managed care entity is going to enter into a relationship with an assisted living facility simply because that facility did well on a state survey. Why? Because it is recognized that such a survey tells very little about how well a facility delivers care or how satisfied people are with a facility's services -- two vital concerns of managed care entities and long term care insurance companies.

Consumers also can benefit from such a system. Possibly for the first time, consumers will have accurate and tangible information about how well a facility does its jobs. This information, or report card, could be used by current and potential residents and their families to evaluate facility performance.

Conclusion

Assisted living is an innovative long term care model that is becoming increasingly popular with the public. We are better equipped to serve the elderly and disabled today than previous generations of long term care providers. Medical advancements, gerontological research and technological advancements have given providers powerful new tools, ideas and means for serving the elderly. The assisted living industry is in its adolescence and is still maturing and growing. Government policies should nurture this growth, not stunt it.

While the GAO report has identified areas of concern, I would urge the Committee, or any policymaker, not to regulate an industry based on the performance of a small minority of providers. Assisted living providers have a duty to act responsibly and to deliver the quality of services that you or I would expect for our parents or ourselves. Quality should be measured in assisted living and poor performing providers can and should be rooted out of the industry. NCAL recommends that policymakers on all levels follow the lead of the Assisted Living Quality Coalition. We urge that they model their quality assurance programs after those outlined in the ALQC's quality initiative.

The attached addendum provides a background and history of the assisted living industry.

ADDENDUM

A Profile of Assisted Living

Based on a Scandinavian model for senior living, assisted living first emerged in America during the mid-1980s. The concept of assisted living is still new enough that the businesses that offer it and the states that license it do not agree on a precise definition or name for assisted living. Throughout the United States, assisted living is known by more than 25 different names. Some of the most common are "residential care," "personal care," "congregate care" and "board and care." However, NCAL believes that the licensure term for assisted living is not as critical as the characteristics a facility must have in order to be considered part of the assisted living movement. NCAL believes that an assisted living facility should be:

- a congregate residential setting that provides or coordinates personal services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services;
- designed to maximize residents' dignity, autonomy, privacy, independence, choice and safety;
- designed to minimize the need to move;
- designed to accommodate individual residents' changing needs and preferences; and
- designed to encourage family and community involvement.

This definition is virtually identical to the definition adopted by the Assisted Living Quality Coalition, an important group discussed in my testimony.

Assisted living combines housing, personal services and health care services in an environment that promotes maximum individual independence, privacy and choice. While assisted living residents are too healthy to require round-the-clock skilled nursing care they are typically too frail to live alone. Assisted living residents share the responsibility for their daily activities and well being with a residence staff geared toward helping them enjoy the freedom and independence of private living.

Assisted living facilities provide or arrange for supervision, assistance, and limited health care services to seniors and disabled citizens when needed. Residents can receive help with an array of personal activities, including: eating, dressing, bathing and transferring (e.g., from bed to chair), as well as meal preparation, laundry, housekeeping, recreation and transportation. While assisted living residences usually do not provide 24-hour skilled nursing care, help with daily tasks frequently includes the supervision or

administration of medication by a qualified staff person. Common practice is to deliver health care services as part of a facility's "wellness program" for residents.

Possibly the single most distinguishing characteristic of assisted living is the importance that is placed on the individual person. Our challenge and duty as assisted living providers is to replicate each individual's life as it was before they moved into the assisted living residence. Our goal is to make moving into a facility an address change, not a dramatic lifestyle change. We want our residents to live independent and autonomous lives.

Assisted living services can be provided in free-standing facilities, near to or integrated with skilled nursing facilities, as components of continuing care retirement communities, or at independent housing complexes. Residents typically can choose furnished or unfurnished studio or one-bedroom units with a private or semi-private bathroom. Living units can also be shared with another individual. Assisted living residences can range from a high-rise apartment building to a three-story home. The number of units in assisted living residences varies widely as do the range of services that are offered.

The number and type of staff employed by assisted living residences varies greatly and depends on a number of factors, including state regulations, the number of people living in the residence and residents' service requirements. Assisted living residences employ staff members directly or contract for services with outside providers. A residence staff may include: personal care attendants, nurses, activity coordinators, food service managers, administrators and maintenance personnel. Contract services frequently include: podiatrists, nutritionists, health and fitness trainers, physical therapists, beauticians and physicians.

The Assisted Living Philosophy

The philosophy also emphasizes the right of the individual to choose the setting for care and services. NCAL believes residents' rights should include the right to:

- Privacy
- Be treated at all times with dignity and respect
- Control personal finances
- Retain and have use of personal possessions
- Interact freely with others both within the home and in the community
- Practice religion or abstain from religious practice
- Control receipt of health-related services
- Be free from abuse and neglect
- Organize self-governing resident councils

The Genesis of Assisted Living and the Long Term Care Continuum

Not all that long ago, there was essentially one long term care option in this country -- the nursing home. In the last 15 years we have seen a tremendous diversification of services with the rapid growth of assisted living, home care, and adult day care as consumers have sought services that precisely match their lifestyle, personal needs and health care needs. This creation of a long term care continuum has meant that the elderly and individuals with disabilities have had more options from which to choose than in the past. Diversification has also meant that nursing facilities now concentrate on caring for the oldest and sickest people in our society and has moved many nursing facilities into new areas such as subacute care. What I have seen occur in 20 + years is an evolution where the chronic or rehabilitative hospital patient of the 1970s is nursing facility patient of the 1990s and the nursing facility resident of the 1970s become the assisted living resident of today.

Assisted Living Residents

The "typical" assisted living resident is an 83-year-old woman who is mobile, but needs assistance with one or two types of personal activities. Although most elderly assisted living residents are female, due to women's longer life expectancies, 26 percent are male. The "average" age of elderly residents, women and men combined, is 83 years according to a 1998 NCAL survey.

That survey also found that while 26 percent of all residents needed no help with activities of daily living, others did in varying degrees. On average, assisted living residents needed help with 1.7 activities of daily living as compared to 3.7 activities of daily living for the typical nursing facility resident. The table below provides additional details on the common activities with which assisted living residents need help.

Personal Activities	Independent	Some Help	Dependent
Bathing	33%	47%	21%
Dressing	53%	32%	15%
Transferring	78%	13%	9%
Toileting	73%	17%	10%
Eating	87%	9%	4%

NCAL's survey also found a full 89 percent of assisted living residents needed or accepted help with housework, while 80 percent needed or accepted help with their daily medication. Residents arrive from a variety of settings, according to the NCAL survey, with most residents moving to facilities from their homes

Assisted Living Financing

Costs for assisted living residences vary greatly and depend on the size of units, amenities, services provided and location. NCAL's latest survey found that 49 percent of all assisted living facilities charge between \$1,001 and \$2,000 in average monthly rent and fees. Another 26 percent charge between \$2,001 and \$3,000 and 7 percent charge more than \$3,000 each month. A full 18 percent charge less than \$1,000 per month.

About 81 percent of assisted living services are paid for with private funds, making the assisted living industry highly sensitive to marketplace forces. The Supplementary Security Income, Older Americans Act, and Social Services Block Grant programs pay for some assisted living services, while about 35 states reimburse or plan to reimburse through the Medicaid program to pay for some service components. We fully anticipate Medicaid and other public programs will have a greater role in assisted living financing in coming years as the industry matures.

NCAL believes that people should have access to assisted living services regardless of whether they have the means to pay for the services themselves. To that end, NCAL supports public policies that allow people to have the resources necessary to access long term care services and the right to choose where they receive those services. NCAL also believes that states that opt to include assisted living as part of their Medicaid programs have a moral responsibility to ensure they adequately support facilities at levels that ensure the delivery of quality services will not be jeopardized.

Other payers will also play a greater role in financing long term care in the future. Increasingly, assisted living is included as a covered benefit in long term care insurance policies. While managed care still plays a limited role in assisted living, there will be a greater reliance on assisted living to provide services to people covered by managed care plans that include long term care coverage. Currently, about five percent of assisted living residents pay for at least some of the services they receive through managed care programs.

The CHAIRMAN. Thank you all very much.

My questions will not be directed to any one specific person. I would ask any or all of you to respond, but you all do not have to respond to each question. Let me know if you do want to respond by raising your finger so I do not pass over anybody.

Assisted living is a unique approach to long-term care. In all other long-term care settings, staffing seems to play a key role in ensuring the quality of care. How much does staffing play a role in what you consider to be a high quality of care?

Mr. PAINTER. Staffing is critical and staffing is becoming an even more critical problem in many areas where low unemployment rates are making the supply of staff almost impossible to find. Adequately trained staff, which has training in medication monitoring, for instance, staff which is trained to handle difficult resident behaviors, staff which is equipped with the proper sensitivity to changing resident needs, is also critical. All of those components go together to make a staff which is effective and which will deliver the care that the resident needs.

The CHAIRMAN. Mr. Lasky.

Mr. LASKY. Mr. Chairman, that is what our families pay for, and when we talk about marketplace assisted living and we talk about large, beautiful residences, at the end of the day, what we are selling our family members and our seniors are services, and many times when we look at the profit and loss statement on assisted living residences, 40 cents of every dollar is spent on staff.

The only way to really allow acuity creep and to provide services and wrap those services around a resident as they age in place is to move up and ratchet that staffing pattern. We do that with an assessment tool, and when that assessment tool is reviewed, there is a subsequent staff add for services. So that fluid ability to move staffing up and down around a resident population is what is unique in our industry and why a formula of one-size-fits-all will not work.

The CHAIRMAN. Mr. Downey.

Mr. DOWNEY. Staffing, since our associates are delivering all the care to our residents, staffing is essential across the board. I think, first of all, you have to hire the right staff. You have to have the right procedures in place so you can select appropriate staff to care for your residents. You have got to train them to do the kind of care you expect them to deliver, and that really requires different training for specialized Alzheimer's care staff compared to assisted living staff.

I think you have to have the ability to add staff as residents need more care, and our process is similar to that which Bill described. We continually assess and reassess our residents. As their needs increase, the staffing ratios are increased in the facility to address those greater levels of need.

The CHAIRMAN. You remind me of a follow-up. Do you experience the same turnover of staff in a assisted living facility that nursing home owners tell us about, and if you do not have that sort of turnover, how do you keep your turnover rates down?

Mr. DOWNEY. I am afraid I cannot cite you a comparative statistic.

The CHAIRMAN. Is there anybody that can respond? Let us start with you, Mr. Lohr.

Mr. LOHR. The equation for calculating turnover rates varies from one multi-facility to another, so that is dangerous ground upon which to tread. But I will comment that assisted living, to some extent, experiences the same types of turnover rates.

Interestingly, though, as it relates at least to the company that I operate, what we will do is we may turn over one position several times during the course of a year and the average employee will stay with us for a much longer period of time. But when the calculation of turnover rate is put into some type of formula, quite often, it looks like the turnover rate is higher than it really is. It is usually in one or two positions.

Mr. LASKY. Mr. Chairman, I worked for two national nursing home chains and was a former nursing home administrator. Turnover is very high, as you know, and I am sure you have heard in this hearing room, but when you think about the employee who is working in our residences, they are making the same choices that our seniors and family members are making. With the desirability of assisted living, the environment, and the flexibility of that staffing pattern, I really think, as an industry, we get the same benefit for attracting employees, for retaining them, and having a lower turnover rate than what my experience was in the nursing home industry because of all the same features that attract our families and seniors to our residences.

The CHAIRMAN. What role do you see for long-term care ombudsmen in assisted living? Do you see them as a helpful problem solver or more so as just part of a regulatory team? We will start with Reverend Painter, and then Mr. Lohr.

Mr. PAINTER. We have had ombudsmen in our program from day one, since the Medicaid waiver program was created in 1984. The ombudsmen program has been very successful and is very strong, but as was mentioned earlier by the State representatives, seriously underfunded, stretched.

But we have found that it has been a very good resource working both directions. The resident has a place to go in terms of their concerns, but we also as management have a place to turn to. When we have not been able to work something out between resident and family and ourselves, we can often bring in the ombudsman to sort out the differences and really achieve a change in the plan of care.

The CHAIRMAN. Mr. Lohr.

Mr. LOHR. The Federal Government is looking for ways to achieve certain conformities, and perhaps one of the best ways to do that is to make sure the ombudsman program is working in every State because they really can be your emissaries in making certain that the circumstances described by my colleague are addressed efficiently, effectively, and certainly on a timely basis.

The CHAIRMAN. Mr. Lasky.

Mr. LASKY. Mr. Chairman, I would like to add that one of the previous panelists talked about the benefits and the difficulty of having nursing home surveyors come into our residences, which happens in many States. The ombudsman program is clearly an excellent way to give a voice to vulnerable frail adults. As Senator

Wyden mentioned before, not everyone can vote with their feet. I think we want to be careful that the past practice and our past use of long-term care is busted loose when we try to bring in an ombudsman from that system and have them really be an enhancement for somebody as a customer.

The CHAIRMAN. Senator Breaux.

Senator BREAUX. I think the panel very much. We have 17,000 or so nursing homes that are regulated basically by Medicare and the Federal Government. We have about 11,000 or 12,000 assisted living facilities that are not regulated by the Federal Government nor Medicare. The complaints about both are basically the same. There is nothing we have heard here from GAO that is different. We have heard examples of familiar problems. Any time you have that many facilities, you are going to have a number of problems. That goes without saying.

The question is, do we try and match what we do in nursing homes to what we should do in assisted living? I would be concerned if I was in the business, as you gentlemen are, with 50 different sets of rules and regulations that you have to worry about in each State that you operate. Is there a solution here that would include one national standard and then State enforcement for assisted living facilities? It seems to me that it would be a problem to cope with 50 different sets of rules and regulations. Any comments from the panel?

Mr. LASKY. I will offer a solution, Senator, and that is when we look at the fabric of our long-term care system right now, the largest customer in the nursing home industry is the Federal Government. The biggest difference with assisted living in my company, where we have almost 370 facilities, is we have 16,000 customers.

So we would rather deal with the nuances of regulation State by State and have the customer empowerment as a vehicle for looking at the solution. I think we need to fund people, not providers. That way, residents that would have that empowerment, the market force and the ability to shop, the dollars would fund the residents and clearly more residents would be able to vote with their feet.

Senator BREAUX. That is not to say there are not standards and guidelines. Are there any States that have no licensing requirements that you are aware of? I mean, every State has some standards? Does every State require that you get a license to operate?

Mr. LASKY. We are licensed in every State we operate in, and that is 33 States.

Senator BREAUX. Thirty-three States?

Mr. DOWNEY. We are, as well. We are licensed in every State, as well.

Senator BREAUX. Are there any States in which someone with a couple of bucks or with some money can go in and do an assisted living facility without having to get a certificate or a permit to do so?

Mr. LASKY. You can, as an operator, choose to go into some select States and, in essence, set up an unlicensed facility but then have licensed home care really be the health care provider in that operator. So you can create a congregate living situation where a licensed home care agency monitored by that State would actually be the care provider in that particular living situation.

Senator BREAUX. We were talking about this up here, and the best enforcement tool has got to be a well-informed public. Because if you have a bad assisted living facility, consumers are not going to go there. But the question is, do we give them enough information to make that choice?

Let me go back to all of the information that is available for every product that we use except those related to health care. If you want to buy a microwave or a toaster or a washing machine, you can get more information than you ever wanted just by going to Consumer Reports. They will have a complete survey of how soon a product breaks, how much it costs to fix, how long it is expected to operate, how much it costs.

But if I wanted to find that information for assisted living facilities, it would be very difficult. Many of these decisions are made on the spur of the moment. They are made by talking to one or two people. Yet, the purchasing public of this very important health system really does not seem to have access to the type of information that allows them to make the most informed decisions.

As I have said so many times, bad information or no information leads to bad decisions. Ombudsmen. I will bet you most people do not even know there is such a person. We do have ombudsmen and they oversee do both nursing homes and assisted living facilities. So they are overworked, and I will bet their information does not get disseminated very widely. If it does, people do not really know how to access it and how to understand it.

So the real challenge, I think, is to find out how we create a better informed public. I would like consumers to all have that little brochure, just like in Consumer Reports, where they could find out as much information as we do about products.

Mr. LOHR. Senator Breaux, if I may, such a brochure is available. It is the beginning of what makes a lot of sense, particularly when it is compared to your comments.

Senator BREAUX. And what is that?

Mr. LOHR. This is a consumer guide to assisted living and residential care facilities that is published by NCAL. I believe we have made these available to your staff members. We certainly can make them available—

Senator BREAUX. And that is put together by the association?

Mr. LOHR. Pardon me?

Senator BREAUX. That is put together by the association?

Mr. LOHR. Yes, the National Center for Assisted Living.

Senator BREAUX. I mean, that would be like me putting out a voting record on myself. Oh, you are great. He does a great job. Go out and vote for him every time you have a chance.

Mr. LOHR. I would encourage anyone who is interested in reading the manual, because it is probably very, very helpful just because of the reason you stated.

Senator BREAUX. By and large, we do that, too.

Mr. LOHR. The other reminder, if I may, is I mentioned in my testimony a report card, a report card that is developed mutually by government, State government, and by providers. The nursing facility industry is doing it in some States. They are going to be doing it in more States. And in terms of credibility, if you have State government and providers working together to establish a re-

port card, put it on the Internet, as has been mentioned earlier today, have it be available in a lot of different ways, they all make a lot of sense.

Senator BREAUX. I think that is a good suggestion. I do not want to say that people who are in the business cannot participate in trying to help regulate and put out the information. Without your participation, it is not going to get done. So if we had someone collecting this information and looking at it from the big picture and not just from the individual company, I think that would be very helpful.

Mr. Downey.

Mr. DOWNEY. I think we at this table agree, information disclosure is a new challenge. Frankly, we have grown at a tremendous rate. We have got a diverse range of assisted living alternatives with diverse structures. Now we really need to get the information out to the consumer in a clearly understandable format, and I think that was our intent in terms of our two associations in putting this disclosure statement together. We are encouraging our members to all complete it so the consumer does have a piece—

Senator BREAUX. This is very important, because I will tell you, in the absence of this type of an operation, there are going to be a lot of members of Congress that say, well, the best thing we can do in this industry is throw them into HCFA micromanaging everything you do. I just have to believe that you do not want to do that.

Mr. DOWNEY. I also think the Internet alternative is a tremendous idea and should be explored.

Senator BREAUX. Senator Wyden and I were talking with Senator Grassley. If I am making that decision for my father or for my mother-in-law, of course, my mother-in-law, her assisted living is at my house and we accept no complaints there. It works out really well.

But I would want to say, all right, where can I find out in my State what are the top ten assisted living facilities? Where can I go to find that out? Everybody in our generation pretty much at least has a basic understanding of the Internet and could plug in assisted living facilities and get the pros and cons of each one. That would help me make a decision that X is better than Y and Y is better than Z and make sure you do not ever go by C because it is terrible. That type of system to access information, I think, would be a great, great contribution.

I do not want to belabor it, because the little red light is on. Any comments on that?

Mr. LASKY. Senator, I would like to add that the reason we are here is because of customer rights. Think about what has gone on in our country in the last ten years. What other time have citizens reached past an entitlement program where their parent could live in an institutional facility for free and paid for an alternative? It is because of that customer firepower and that energy that we are here today and we have a new long-term care movement.

We at this table will pledge our industries and our trade associations to work with the committee that does anything to enhance customers' rights and information, and we are willing to take the business risk and welcome the business risk and stay on that side of the assisted living movement.

Senator BREAUX. Reverend Painter.

Mr. PAINTER. I just wanted to make a pitch, if you will, for the part of the market that is really not too well represented. This is the wide number of individuals who are basically shut out of the assisted living market because of cost, that without some form of third-party payor, whether it is tax credits, expansion of the Medicaid waiver programs, et cetera, together with developing an integrated home and community-based services program that makes sense for individuals in the least restrictive environment possible most will be left out.

We are doing a disservice to the biggest segment of the market. These individuals need this level of care. They benefit from it greatly. I just really want to make a very strong appeal that you consider, if you are looking at this industry, that you also consider ways of facilitating access among the less advantaged. Thank you.

The CHAIRMAN. Senator Wyden.

Senator WYDEN. Thank you, Mr. Chairman and Senator BreauX. You and I are all thinking in exactly the same way on this information issue. I want to frame it even more specifically.

If you look at page 15 of the GAO report, they say, for example, of the facilities that they surveyed, "only one in three contain information about services not covered or not available, the facility practice for monitoring resident needs, or the circumstances under which the cost of services might change." They go on to make other claims of the same sort.

We had talked earlier about the use of the Internet and I would like to ask each of your associations to go out and ask your members in the next 90 days to try to get that information on the Internet. It seems to me that when the GAO comes forward and outlines specific areas where they have documented consumers not getting information, we have got a problem. We do not need a whole lot of bills and programs. Senator BreauX is absolutely right about that. Senator BreauX and Senator Grassley and I have all been talking about the same thing.

I would just hope, particularly at page 15 of this GAO report, where they talk about specific areas where consumers and families have been kept in the dark, where you all would go on out and just say, in the next 90 days, we are going to tell the members of our associations to get that information on the Internet. Is that something that is doable, Mr. Lasky?

Mr. LASKY. Well, Senator, we cannot give our customers too much information. When I see those lines that customers are not getting that, I really feel we have not lived up to our duty, taken care of a sensitive and a frail population. We are here today and the consistent message you have heard from all four of us is to protect the rights of customers and the empowerment of customers. That is what has fueled our assisted living movement.

So we are happy to pledge to this committee on behalf of our industry, and I will speak for people on either side of me that the way for us to protect what has happened here in this \$13 billion movement and to move it forward to get past these issues is to keep the focus and keep the laser beam on informing customers, of living up to our duty of taking care of a population that all of us as Americans care so much about and want to be protective of.

Senator WYDEN. So can we get it on the Internet in 90 days, your members?

Mr. LASKY. I do not know if we can get it on the Internet in 90 days, but we will pledge to achieve that goal.

Senator WYDEN. All right. The second question I had deals with what I saw this weekend and what I have seen in Oregon, as well. I was in a very good assisted living facility. I think you have heard me say that throughout the course of the last three-and-a-half hours, and I have seen plenty of them in Oregon.

My question to you is, what do we do with the relatively small number that are not adhering to the kind of standards that you all have talked about as important and do it in a fashion so as to not weigh down the responsible facilities and cause them to have to add to their costs that could go to serving patients? I think that this is the central question here. It comes up when you talk about accrediting organizations. What do you do when the responsible people are plenty willing to comply and how do you figure out a way to weed out the bad apples for which you do customarily need some government and need some enforcement capability? That is really my last question.

Mr. Downey, what is your answer to that?

Mr. DOWNEY. I think we have heard from other witnesses on the other panels that in many cases, States have adequate regulations or extensive regulations. There may be issues of enforcement. So one question is, are the regulations that are already in place being rigorously enforced?

I guess another dimension of it is, are the problems that assisted living communities are experiencing, are they disproportionately concentrated in a certain type of facility? Are they disproportionately concentrated in a board-and-care type of facility? In some cases, States have moved to create different categories of regulation. They recognized that different facilities have different capabilities and should be regulated in different ways, and I think that is an approach that we have seen as positive in the States that have pursued it.

So I think the bottom line position is that if facilities are chronically and seriously delivering inadequate care, they should be shut down and they need to be shut down and the States need to have adequate enforcement resources to identify them and move against them. So I think it is a question of enforcement and potentially looking at a different structure to the regulation.

Mr. LOHR. And also, this relates once again to information. You would, if you were buying a microwave oven, you would look at the information available and you would say, I am not going to buy that one. I am going to consider buying either of those two. The same can happen here with information, good quality information being available to our consumers, to our customers.

Senator WYDEN. My light is on and I will leave you with this thought. I hope, also, within your associations you come down with hobnail boots on those that are not adhering to good standards. I will tell you, the toughest thing, and I do not care whether you are a member of Congress or whether you are in the legal profession or the dental profession or the accounting profession, is to say,

there are people in our organization who are not adhering to the standards.

There is a role for government. But I will tell you, the best way to send a powerful message about high standards is when you have the handful of people who are not adhering to the standards, you boot them out and you say, this is not what we want to be the reputation of assisted living. The partnership works two ways. We will look at a responsible role for government, but you are going to have to send some messages. When the GAO comes up with the kinds of reports that we have seen here and documents these kinds of instances, you have got to go back and say, we do not want this kind of work in our association and it taints the majority of people who are doing a good job.

Mr. Chairman, I thank you, and again, I think this has been one of the best hearings we have ever had.

The CHAIRMAN. Senator Kohl.

Senator KOHL. Thank you, Mr. Chairman.

This first question is primarily for yourself, Mr. Lasky. As all of the industry representatives have highlighted in their testimony here today, quality of care and consumer information are high priorities for the assisted living industry. One issue that I have been particularly interested in and that you have all stressed here today is the quality of staff that work in health care facilities.

As you, Mr. Lasky, know, the Milwaukee Journal Sentinel wrote a series of articles in 1997 about how easy it is for people with criminal and abusive backgrounds to find work in long-term health care. As you may or may not know, I have introduced legislation to require background checks for workers in long-term care facilities that receive Federal funds. Wisconsin has enacted a much further-reaching law that requires nearly all health care facilities, including assisted living, to conduct background checks on their employees.

How big a problem is the staff for assisted living facilities, both in Wisconsin and nationwide? How is the background check law working in Wisconsin? And in States that do not require background checks, how do your assisted living facilities screen employees to assure that they do not have criminal or abusive history in their background?

Mr. LASKY. Senator, it is working very well in Wisconsin and it is working very well in many of the States in which there is a law, and we typically do that as a background check on our employees. It clearly does set a bar for people to have to leap over to be able to take care of these frail seniors in our residences and sends a very strong message that anything in your history that has you fall below that, you cannot take care of someone that is frail.

So I think it is an example of setting a standard for those that are taking care of our seniors and you can hear from me that it is working. I think it is clearly setting a low bar of what someone should really have as a requirement for working with our seniors. Clearly, the quality of staff issue is everything we have talked about here. It is everything that we talked about in the GAO report.

The example that Senator Wyden gave on what is missing in some of the nasty stories in the GAO report are not about lack of

regulations. Those regulations exist State by State. They already have the power for enforcement. They already have the power for recourse for problem providers. It is that lack of follow through.

So, clearly, anything we can do that enhances what we pay our employees and enhances the qualifications of those employees will be felt by our seniors in these residences.

Senator KOHL. Okay. Another question is for all of you. I am concerned about the lack of access of lower-income people for assisted living. The vast majority of facilities are private pay, as we know, and the average monthly rate can range anywhere from \$1,000 to \$4,000 a month. Most lower-income families could never afford the option of assisted living. How does the industry plan to take steps to make assisted living available to lower-income people? Mr. Lohr?

Mr. LOHR. That is a very difficult question. I will give you some examples of possible solutions. In our company, we dedicate a certain number of beds, if you will, in each facility for residents who do not have the resources to pay what would normally be the rate for that facility. In a way, it is a small effort, but it is our contribution to the community and recognizing that it is very, very difficult.

Florida is doing some very innovative things as it relates to a Medicaid waiver program. Those types of things can continue. We can work with States as they create innovative methods of looking at how to spend their dollars for their citizens.

Ultimately, it really becomes a circumstance of one where not every facility has to be a Cadillac. There are good facilities that are Chevrolets. We have to recognize that we can do it that way. Particularly, we can do it that way if government, State government, is working with us to try to solve the very problem you have identified.

Senator KOHL. Okay. Mr. Lasky.

Mr. LASKY. Senator, earlier we heard testimony from one of our family members who is also a professional that in the State of Florida, some providers are being paid by that State to take care of residents for \$22 a day. How we think we can take care of any senior with their room and housing and then around-the-clock services and professional health care services for \$22 a day is absolutely ridiculous.

The only way we are going to be able to make assisted living accessible for those that do not have access today is to allow for funding that is portable, funding that follows the person, where the individual is allowed to pick where they want to live, is allowed again to be a shopper and have customer empowerment, as well as allowing family members to add additional dollars on top of that payment system. It is illegal today in this country within the Medicaid waiver program to add dollars as a family member on top of what the State and Federal match mandated dollars are.

There are many good, clever ways for us to go into the next millennium with a clean slate on how funding can be portable and how there can be variety in funding and give people greater choices. But we have to start with the premise that you cannot take care of a senior for some of the rates we are doing in State mandated systems.

Senator KOHL. Reverend Painter.

Mr. PAINTER. I would like to build on that comment. What Dr. Mollica indicated earlier, also, was the fact that many States are pressured in terms of their own State budgets to either cut or cap the funding for the waiver programs, which results in the \$22 a day scenario.

In my State of Colorado, we have had an excellent program which has had peaks and valleys and plateaus in funding. Currently, we are receiving, including the resident portion from SSI, \$1,390 a month. Our cost for that same unit—cost, not charge—our cost is about \$1,450 a unit currently per month. It means that the State is reimbursing at a level which is below our actual cost. The State has projected an increase of two percent for the year ahead, on July 1 of this year. That two percent will not anywhere begin to include the cost of salaries, support, and line staff for that facility.

So, basically, helping States to address this problem from a fiscal perspective in terms of either linking that with the amount of long-term care per bed cost in that State so that it works up proportionately in gear with that same system would go a long way.

Expanding the tax credit system, making that more applicable to assisted living, the conversion of HUD units and just a variety of mechanisms are needed, because, as I said earlier, without a third-party payor of some sort, we cannot deliver this product to the low-income population. I have a HUD facility, 162 units, 40 percent of those people need assisted living, but do not qualify for Medicaid, and will not be able to access assisted living and they will go directly from the HUD facility into skilled care. That, to me, is not right.

Senator KOHL. OK. Mr. Downey, do you have a comment?

Mr. DOWNEY. At Marriott, we have a range of different types of assisted living communities with costs ranging from about \$1,500 a month all the way up to over \$3,000 a month. But we have found that we cannot really deliver a quality assisted living product for much less than \$1,500 a month. Now, that is well above the reimbursement that is currently available under many State programs, so, obviously, there is a gap between the cost to provide the service and the funding that is currently available.

You have heard some creative ideas in terms of potentially bundling other programs, HUD housing with home care, providing a portable benefit where the resident would get home health care in another subsidized housing setting. All these could potentially be solutions. But short of expanding direct funding, I do not know how effective they could be.

Senator KOHL. Okay. My last question is, building on what you have said, it seems almost inevitable that we will soon hear some people call for the Federal Government to help seniors pay for assisted living, and if that happens, the Federal Government would then want to make sure that the money is spent wisely, to ensure that these facilities were providing the highest quality of care.

I realize that you most probably much prefer State regulation to Federal involvement, and I am not advocating Federal regulation of assisted living, but how could we imagine that the Federal Government would provide a considerable amount of money without also requiring some considerable amount of oversight?

What do you think, Mr. Lohr? Would you like to have the money and the oversight, or would you rather not have the money and forget the oversight?

Mr. LOHR. I want to do the right thing, which I believe is send guidelines, not standards, to the States. Pick those things where conformity is necessary and give them to the States and tell them to do their job as it relates to the guidelines and also to the dollars that are flowing from the Federal Government. Let the States then do the right thing, just as I have suggested I would want to do.

Senator KOHL. Mr. Lasky.

Mr. LASKY. I will give an example, Senator, and that is when we take a payer system where you put that coupon in the customer's hands, that is the best measure of quality day to day. The food stamp program in this nation does not mandate the width of hallways or the lighting levels of a grocery store, and we are able to give customers empowerment and access to a health care service just like we have with other entitlement programs.

The States do regulate us. We are surveyed. And even under the Federal regulations for the nursing home industry, the Federal Government still relies on the State surveyors to do their reviews for them.

So I think, again, the repetitive theme here is we need to fund people. They can then vote with their feet. They can make choices. And all the power you have in other segments of industry, where you shake out who is doing a good job and who is not doing a good job, is much more easily taken care of in our nation on that basis. So I really think the regulatory framework is there and our methodology of how we create access is what we really need to look at.

Senator KOHL. Okay. Reverend Painter, do you have a comment?

Mr. PAINTER. The regulatory framework is there in the waiver program. For instance, in terms of just my particular facility, I have both a license under the personal care boarding home regulations for the regular assisted living private market program, but we are also certified as a Medicaid waiver facility, in which case the staffing ratio is, in fact, specified, where it is not under the personal care boarding home regulations. So the standards are higher and tougher for the Medicaid waiver program than they are for the regular assisted living program in our particular State.

So there are vehicles available that I think we can work with. I think the hook, as I just tried to explain a few minutes ago, is in the State budget process and the problems that States are having, many States, at least, even with a budget surplus, of being caught in this crunch between the mandated need to return a good part of that surplus back to the taxpayer as opposed to investing it in some of these programs. So we need to solve that dilemma and I think we can move forward.

Senator KOHL. Okay. Mr. Downey.

Mr. DOWNEY. Your question, I think, is what regulatory kinds of solutions or structures would really give the Federal Government confidence that their money was being well spent. In some respects, I think it is the same question we have been talking about. What regulatory structures are most appropriate for assisted living in general?

We have talked about alternative approaches that the Assisted Living Quality Coalition has identified, focuses on outcome measurements and satisfaction measurements as opposed to highly prescriptive requirements. I think all of these things could potentially provide an appropriate and satisfying substitute without repeating the mistakes that we have experienced on the nursing home side. So I think what we want to do is protect the flexibility, protect the variety, protect the customer choice, but at the same time ensure an adequate standard. I think there are ways to do that without repeating the same mistakes of the past.

Senator KOHL. Thank you, members of the panel, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Kohl, for your kind attention to the work of this committee.

I am going to just have one question and then we will close, and that is to any or all of you, again, like I said. We know from experiences with nursing home care that much of the time, families have not planned for long-term care needs. They often cannot pay for the care and subsequently their care is financed by Medicaid. I understand that a number of tax-qualified long-term care insurance products in the market offer coverage for assisted living services. Is the industry taking any additional steps to promote financial planning for long-term care needs?

Mr. LASKY. I will jump in here, Mr. Chairman. We have, as a trade association, sat down with different long-term care providers, some of the largest. Our company has family members and residents today in which we get an insurance check to pay for our care. I think there really has been a shift in our society that if you want variety and if you want choice, we as a society, as Canada is now learning, are going to have to plan and be less than 100 percent reliant, like we all grew up, that the Federal Government is going to take care of us entirely when we are frail.

So we have seen that shift, and the reason we have an industry today is because seniors and family members decided to pay for something when they could have received it for free, and I see all of the ingredients churning at a high level where people are buying insurance plans, and we as a trade association have sat down with those carriers.

The CHAIRMAN. Yes, Reverend Painter.

Mr. PAINTER. The product has been along for a long time and has not been particularly successful commercially, partly because the younger population, where it is affordable, chooses not to use it. The older population that needs it, it is not affordable for them. So we need to find ways to bridge that gap. Certainly, some feature of tax credit availability or some type of deductibility could be certainly helpful in that area. Working with families to, again, plan ahead, ahead of the need, is really effective, but it is a tough nut.

The CHAIRMAN. Mr. Lohr.

Mr. LOHR. I also believe we are seeing the front end of that type of insurance activity really starting to take effect. People who are 55, 60, 65 years of age are now buying this insurance, and our typical resident is 83 years or so of age. So it is going to be a while until it really comes of age, so to speak, but we are beginning to see activity and it is really a positive sign.

The CHAIRMAN. Thank you. I thank all of the panel members here for your addition to the information we have and speaking for your industry. Obviously, I thank all of our witnesses today of the other two panels.

I also especially thank the GAO for completing a very difficult task. Some months ago, we asked the GAO to gauge public concerns with large new and private industry. Their findings should be of great interest to anybody considering assisted living for themselves or for their family members.

First, we learned that assisted living is popular and consumer demand is very much on the rise. Assisted living is expected to keep growing as more and more families shop for long-term care. That is why it bothers me that too many people may lack the information they need to choose a facility that is just exactly right for them.

As we heard, half of the facilities studied by the GAO do not provide prospective residents with key information such as how much help residents can expect with medications, the circumstances under which the cost of services may change, and when residents might be required to leave if health changes.

Equally disturbing is that only 25 percent of the surveyed facilities routinely provide consumers with written contracts prior to their decision to apply for admission. According to the GAO, this document is an important source of information. In some cases, it may be the only place where information about discharge policies or costs appear. The citations for quality of care problems are worrisome.

Individuals seeking assisted living have varying degrees of needs of assistance. Some residents continue to live very independently and seek only to enjoy the social aspects of assisted living. Others might require help with essential everyday activities, such as getting dressed or taking medication. In all cases, assisted living is a new home, and in most cases, most residents view nursing homes as the last resort.

Coping with long-term care needs can be challenging. Finding a new place to live is also a challenge. Many people shopping for assisted living might not know what information to seek to help make those decisions. It is important and fair that the fine print contains no alarming surprises.

The obvious question is what will this committee do next? We have learned a great deal today about assisted living. While the GAO answered some important questions, it also raised many more questions, as well. Most importantly, I want to learn what States are doing to ensure that assisted living is a viable, affordable, high-quality option in the long-term care continuum.

My initial step in this process of learning more will be to pose a series of questions to all 50 Governors. I will do so in writing and then we will analyze their responses. In this letter, I will ask each Governor to take special note of the importance of consumer information. This point was made by each of today's witnesses, including family members as well as each witness representing industry.

Some of the observers will ask whether we will consider Federal regulation of assisted living. Above all, it is important to keep in mind that the assisted living market is primarily a private pay

market. For this reason, a Federal role, if any, is very small. As we learned today, the responsibility of regulated assisted living quality belongs to the States. Nevertheless, it is important that we do all we can to ensure high quality of living for older Americans. Holding this hearing is an important way for Congress to stay informed.

Second, I look forward to monitoring the industry's efforts at self-policing, and we heard today that the industry stands committed to correcting any shortcomings that might be there, as well as getting more information out to the public at large.

More immediately, I urge every assisted living consumer to shop carefully. Assisted living can be a tremendous service under the right circumstances. I have a list of consumer recommendations that I have put together called "Friendly Tips for Assisted Living Consumers." I hope that this will be useful, as well.

In closing, I would like to remind everybody that assisted living is a welcome development. The long-term marketplace demanded innovation and an industry has responded. I hope the problems that have been identified today will not grow with the assisted living industry.

Thank you all very much, and the committee is adjourned.

[Whereupon, at 4:30 p.m., the committee was adjourned.]

APPENDIX



CONSUMER CONSORTIUM ON ASSISTED LIVING

**“Shopping for Assisted Living:
What Consumers Need To Make the Best Buy”**

**Hearing of
The U.S Senate Special Committee on Aging
April 26, 1999**

Written Testimony of:

**Consumer Consortium on Assisted Living
Rhonda Buckner, Executive Director
with
Lou Kilby, PhD., Consumer
Trudy Sine, Consumer
Pamela Schuman, Executive Director,
Ventura County Long Term Care Ombudsman Program**

◆ RESOURCES & NETWORKING FOR QUALITY ◆

P.O. BOX 3375 ARLINGTON, VIRGINIA 22203 (703) 841-2333

Introduction and Recommendations

CCAL, the only national consumer advocacy organization solely dedicated to voicing the needs of residents of assisted living, believes that the GAO report on assisted living provides compelling reasons to more closely scrutinize the industry and its commitment to quality care. CCAL urges Congress to expand the Long Term Care Ombudsman Program, under the Older Americans Act, to increase the protection of residents in assisted living. Providing adequate funding to ombudsman programs nationwide and specifically directing their efforts towards assisted living will greatly enhance consumer protection.

CCAL further suggests that town meetings be held around the country to collect more information about consumer experiences and to solicit a wide range of input about the usefulness and direction of national standards.

The assisted living industry is in its adolescence. It is growing very rapidly and it is facing major problems. In Florida alone, 85 new facilities opened each month last year. With clear expectations, proper guidance and supervision, the assisted living industry will grow into a mature, responsible industry, providing a major contribution to long term care. If left alone, it is likely that the problems currently faced will grow into the same magnitude of problems that have been faced by the nursing home industry, facilities for people with mental retardation, mental illness, and children without parents. We have seen what happens if problems are neglected.

When the discussion turns to how to ensure quality, the industry argues "let the consumer vote with their feet." That is, if consumers don't like the services they are receiving, or if they don't get what was promised, they will move. However, the typical consumer is 83 years old, frail, and may have some form of dementia and therefore cannot easily relocate. Consumers are too vulnerable for the government to take a "hands off" approach. As Senator Wyden said, the GAO report is a "wake-up call." Congress needs to act now, before the problems spread even further and become epidemic in nature.

There is no single answer. As a beginning step, CCAL urges the Committee to recommend that the role of ombudsmen in assisted living be expanded so that assisted living residents receive greater protection by increasing external monitoring of conditions and treatment in facilities. Expanding the ombudsman program will also give residents and their families a voice to express their needs and concerns.

Currently, ombudsmen's ability to advocate for residents of assisted living is hampered by inadequate funding and lack of authority in some areas. While ombudsmen are mandated for nursing homes, they are not required for all assisted living. All programs need increased staff to address the increased responsibilities that proper monitoring of assisted living demands. The need for ombudsman has increased dramatically from when they were only addressing nursing home issues.

Ombudsman can only be effective, if residents and their families know about their existence and their role. It will also be important to require facilities to periodically inform residents and their families that ombudsmen are available and to explain their role.

Assisted Living Must Be Accessible to People on Low and Moderate Incomes

Although not a subject of the GAO report, the issue of affordability did get raised in the Senate hearing. Assisted living is only affordable to about 15% of the population who need it. It is largely a private-pay industry. Although the industry estimates that the national average monthly fee is approximately \$24,500 per year, that does not reflect the full burden that many residents are paying. Additional fees are often charged for medication assistance (see attached letter from Dr. Lou Kilby), increased levels of care, delivery of meals to the room, continence products, and other products and services. In major urban and suburban areas, \$36,000 to \$50,000 per year is common. At the Jefferson, a Marriott facility in Arlington, VA, a private room in their Alzheimer's unit is more than \$5,000 per month, or \$60,000 per year.

States are increasingly using Medicaid funds for assisted living, however, in most areas the level of funding is inadequate and the number of people who qualify is very limited. Increasingly, individuals are left to live in their homes without adequate support, or forced to move away from family and friends to less costly rural areas. Attention needs to be focused on helping ensure assisted living is affordable to individuals on low and moderate incomes.

Reports from Consumers, Advocates, and Professionals Support the GAO Findings

CCAL has encountered numerous and serious problems in assisted living throughout the country similar to those accounts in the GAO report. The attached letters from Trudy Sine, a consumer from Ohio and Pam Schuman, the Director of the Ombudsman program in Ventura California offer additional examples of significant problems. A third letter, from Lou Kilby, PhD. of Arlington, VA, offers insight from a resident who is content with her placement; recognizes problems, especially when it comes to staffing issues; and worries about her future. All three individuals would have liked to testify in person. CCAL is including their letters to give increased voice to consumer concerns.

Quality Care

CCAL received numerous reports of poor quality care. Staff often have little or no experience and receive poor training. State regulations often require very little to be an assisted living administrator. In Virginia, for example, one must be 18 years old, of good moral character, and have a GED and one year of experience working with the elderly. In Oregon, a state known as a leader in the assisted living movement, requirements for the administrator are also minimal. Then, these administrators are given authority to determine what staffing is needed for the populations they are serving and other professional decisions.

Facilities have insufficient staff to resident ratios. Evening and weekend coverage is of major concern. High staff turnover thwarts continuity of care. Dr. Kilby's letter notes that there have been five executive directors and seven activity coordinators in the last four and a half years at her facility.

Across the country, people have been admitted without appropriate assessments. Residents' illnesses and falls were not appropriately attended to, residents received incorrect medication; people didn't get bathed when they should, and didn't get the help they needed to eat properly at mealtime. Help with going to the bathroom, and housekeeping duties was

sometimes inadequate. Ms. Sine's letter notes problems with medication and a fall. Ms. Schuman's letter is most disturbing, in that the poor quality of care led to death in one example.

"The food is terrible" is a constant complaint. Lack of fresh fruits and vegetables and poor overall quality are concerns.

- Residents of one facility were served noodle soup, canned ravioli, canned corn, mashed potatoes and one dried inedible pork chop for dinner one night.
- One resident kept ringing for help to go to the bathroom. No one answered, so she tried to go by herself. She fell and later died of injuries related to that fall.
- In Florida, newspapers reported that residents were sleeping in pools of sweat because facilities are not required to use air conditioning.

Marketing Practices

Consumers are ill-informed about assisted living and are often making decisions in crisis situations. There is a built-in tension between the consumer's need for help and the marketing agent's desire for a sale. When an individual goes to an emergency room, he/she does not evaluate the advice of the emergency room staff, they take it for granted that they are getting the best help possible. When buying a product or service, it is understood that the salesperson is just trying to make a sale. Because many consumers are in crisis when they are shopping for assisted living, they approach marketing agents more like the emergency room example. Although marketing agents often appear to be concerned about the best interest of the senior, their goal is the sale.

An example of this problem recently came to CCAL's attention. A daughter in California moved her mother into a facility for people with dementia, following a car accident which caused a head injury. Facility staff had done an assessment and encouraged her to place her mother there. However, her mother did not have dementia and the mother experienced great distress surrounded by people that had limited ability to carry on a conversation. When the daughter realized the problem, she moved her mother to another facility, but the emotional and financial costs of the placement were significant.

Consumers are especially vulnerable to marketing personnel who oversell the facility's capabilities. Marketing staff have not accurately reflected the limitations of facilities to provide care. The aging in place philosophy seems to, but does not really, guarantee that a resident won't have to move again. In addition, marketers do not always clearly state all of the fees charged for care. They may discuss the monthly fee, but omit details of other fees that residents may incur.

Some facilities changed the services they provide and the costs, from those that were marketed, after the facilities get filled. Oral promises made by marketing directors have not been met when the need arises, and the marketing director is no longer at the facility. Residents have been told that they could live in a facility "forever," yet later were forced to leave because of their care needs. Brochures often feature nurses and other health care personnel, but provide little information about what those professionals actually do within the facility. Consumers sometimes don't look past the attractive surroundings to determine whether there is an adequate level of personal care.

- One facility advertises three nourishing meals per day, but serves no fresh fruit and vegetables. Their marketing material said snacks were available 24 hours per day, but now

locks the snack room so that snacks are not available. Although it's brochure said that professional supervision was available 24 hours per day, there is no trained staff in the facility after 7 p.m.

- A facility's brochure shows a uniformed nurse caringly attending to a resident. While the brochure did not state that there is healthcare oversight, the picture conveys this message. In reality, the facility has a nurse on site a few hours per week. Aides, with only two days of training, administer medications. There is no health care professional reviewing medication records and administration.

Resident Contracts

Consumers have faced serious problems as a result of inadequate contracts and insufficient scrutiny of the documents. When services and fees have not been clearly spelled out, residents have spent all of their money faster than anticipated and have been forced to move. Future services have been promised orally but not in writing. When the resident needed the services, they weren't provided.

- An Ohio ombudsman reports that facilities change residents' levels of care rapidly, with no advance notice that a rate change will occur.
- Legal Services of Northern Virginia studied assisted living contracts in their jurisdiction and found problems with many. For example, contracts varied widely as to the extent to which they disclosed all costs in the contract. Discharge policies protected the assisted living facility from potentially disruptive clients, but did not ensure a resident's right to be free from arbitrary discharge. Contracts inappropriately protected facilities from liability. Finally, a common problem found among the contracts was the ambiguity as to the obligations of third party signatories in the event that a resident is unable to meet the costs her/himself.

Discharge Issues

Discharge policies vary dramatically in assisted living and some consumers have been misled, sometimes resulting in dire consequences. A consumer can spend their life savings over several years and then be evicted because they run out of funds. Sometimes consumers are not given adequate time to plan for a move. Rather than deal with a problem behavior, some facilities will discharge a resident instead. Families and residents are afraid to voice their concerns because they are afraid the resident will be discharged. Currently, there are no outside appeals processes available to consumers of assisted living. Facilities have been known to simply state that they "are offering a service and can decide to whom they want to sell their service."

- An Ohio ombudsman reports that he is receiving numerous calls from residents of assisted living facilities who were enticed to enter assisted living with promises they could remain in their facility regardless of the personal needs. Now that the residents need extensive care, they are being discharged. These residents have exhausted their funds and they don't know what to do.
- One daughter placed her mother in an assisted living facility that had an attached nursing home. Prior to admission, the assisted living facility promised the daughter that once her mother's funds were exhausted, she could be admitted into the nursing facility and Medicaid would pay the bill. When the funds were exhausted, the mother did not medically qualify for

placement into a nursing facility funded by Medicaid, and she no longer had funds to remain in the assisted living facility. There was no place for her to go.

About CCAL

The Consumer Consortium on Assisted Living (CCAL) is a national, consumer focused advocacy organization that works collaboratively with the broad spectrum of people and organizations supporting quality assisted living as an essential option in long term care. CCAL:

- promotes quality care and best practices to enhance the quality of life for all residents;
- advocates for the provision of assisted living for people who are on limited incomes;
- educates consumers, advocates, professionals and the general public;
- provides tools to help consumers make informed choices;
- monitors assisted living issues; and
- serves as a national resource and facilitator for the exchange of information and ideas.

CCAL is a nonprofit, nonpartisan organization that includes: consumers, caregivers, advocates, regulators, care managers, nurses, researchers, providers, educators, elderlaw attorneys, legislators, and other long term care professionals.

Conclusion

Congress should act sooner rather than later. Expanding the Ombudsman Program and conducting town meetings around the country will expand our knowledge and understanding of the problems, broaden discussion of the needed solutions, and help residents and their families receive assistance they need to resolve complaints. Although many residents of assisted living are well served by the facilities they live in, many others are suffering result. **Let these hearings mark a new beginning in consumer protection for assisted living residents.**

April 26, 1999

Rhonda Buckner
 Consumer Consortium for Assisted Living
 P.O. Box 3375
 Arlington, Va. 22203

Dear Ms. Buckner;

Recently I was made aware of a Senate Hearing that will be held on April 26, 1999. This Senate will be hearing testimony concerning assisted living facilities in Ohio, therefore I would like to offer this letter as my written testimony concerning this issue.

My fiancé, Gary, had his mother residing in an assisted living facility in Bucyrus, Ohio. The corporate office is located in Oregon. Gary's mother and the rest of the family were very pleased to learn about such a facility that would assist their family member in her daily needs. This appeared to be the perfect solution, unfortunately the perfect solution did not live up to its promises.

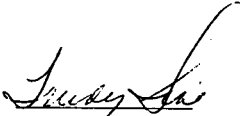
Listed below are a few of the problems Gary's mother encountered while living at this facility.

- Wrong medication was given to her on two separate occasions that I know about. Gary's mother caught one of the mistakes but unfortunately she was given the wrong medication on one of these occasions and had to be monitored for several hours.
- According to her contract, she was to be taken to the dining area for all meals, this was not done and on many occasions she would tell her son that she was hungry.
- According to her contract her apartment was to be cleaned on a weekly basis, this was not done and at one time I was able to determine that the vacuum cleaner had not been used for four weeks. Gary's mother is incontinent of urine and needs to wear depends, these depends would be found on her bathroom floor and piled in her waste basket therefore the staff was not properly disposing her depends.
- According to this facility's contract, a nurse was to be on call twenty-four hours a day. On one occasion a staff member called Gary and informed him that his mother had fallen and had a laceration to her head and the nurse refused to come to the facility and the staff member wanted to know what she should do and Gary informed the staff member to call and have his mother transported to the local emergency room. His mother's laceration required three stitches.
- This facility uses different levels of care in order to determine what pay scale a resident will be placed, the higher the level the higher the cost. Shortly before the decision was made to relocate his mother, the facility raised the level of care. After the facility learned of Gary's mother's plans to relocate, the director offered to lower the cost. Therefore did

Gary's mother need the higher level of care or not?

I would like to state that my present profession is working with the elderly and I have many concerns regarding assisted living facilities. It appears that many are simply in the business for profit and appear to lack the knowledge of caring for the elderly and how to meet their needs. I often wonder who is watching and caring for the residents in these facilities who do not have someone who cares for their best interest. It is a scary thought and one that each of us may find ourselves in some day. Therefore take note of these concerns and the concerns of others before it becomes personal to you or of a loved one.

Sincerely,



Trudy Sine

To: Rhonda Buckner, Executive Director, CCAL
From: Emelia-Louise Kilby, PhD resident Sunrise of
Arlington

Purpose: This paper was written to be submitted to the Senate Special Committee on Aging addressing the positive and negative aspects of Assisted Living.

I am a 75 year old professor emerita from George Mason University who learned about assisted living while recuperating in a nursing home. Realizing that I would not be physically able to return to my 3 story townhouse, I was searching for an alternative.

Now paralyzed and unable to walk, I am pleased that assisted living has made it possible for me to live in a pleasant atmosphere while receiving the physical care I need. It has given me a degree of independence which might not exist in a nursing home.

The home-like facility in which I live is a large, attractive Victorian house with approximately 60 residents. Visitors are impressed and are often heard to say "oh, isn't this nice?" Of course residents pay for this with monthly charges ranging from \$2,000 to almost \$4,000 depending on the size of the suite chosen. A community fee paid once at the beginning of one's stay can be as much as \$6,000. In addition, daily care for me has gone from \$12.50

2)

to \$20 when a new plan was instituted. Within a few months that was changed to \$22 a day.

In this setting I can order and take my own medication. The residents who, for some reason, can't handle their own medication pay \$6 a day for administration plus the cost of their medicine.

There is considerable turn-over of staff even at the Executive Director level. There have been 5 in the 4 1/2 years I have been here. Admittedly the change in 2 cases were promotions. Seven activity coordinators have been part of the staff in the same 4 1/2 years. Keeping care managers is a problem. A resident just gets used to one and she is gone (most are women). The reasons for their leaving seem to be: too much work, too little pay, not having enough hours (they are considered part-time with only 20 hours a week; most taking a second job to make ends meet). This sort of turn-over makes for lack of continuity and is disruptive.

The senior staff and care managers demonstrate real feeling for elderly residents. I am sometimes impressed with how quickly new employees figure out how to help residents even anticipating problems. At other times staff members are so involved they fail to see a resident in difficulty (for example trying to sit on

3) the bar of a walker). Observing that I signal to a care manager or other staff member to go to that resident's aid.

The care managers are the ones who, in a sense, do all the work. Their work is physical to an extent, very demanding with a variety of responsibilities: caring for incontinent residents, shaving men, assisting a resident to brush her teeth, dressing some, serving in the dining room and washing dishes. Making beds, removing trash and doing laundry were recently added to their responsibilities. All this for about ⁴7 an hour.

Too often a care manager calls in sick, or is delayed, or just doesn't show up. This results in a double work load for the one who is here on time. I have had difficulty in getting my assigned bath on occasion.

Communication is often a problem when English is the care manager's second language. Their pronunciation is especially difficult for a hard of hearing resident to understand.

Care managers are required to familiarize themselves with a resident's care plan. New employees learn how to care for a resident by observation. Generally after two observations, they are on their own. In my case I frequently have had to explain the complexities of my care. What I wonder happens to the resident who is less

4)

Knowledgeable or doesn't have the capacity to explain.

Although I didn't plan for this sort of retirement in my golden years, I have been satisfied with assisted living in Sunrise of Arlington. I have had some leadership opportunities and more people to talk with (especially the staff) neither of which I would expect to find to this extent in a nursing home. However, the costs, probably less than nursing homes, are of considerable concern as they keep going up. I fear I will outlive my money.

Emile Louise Kilby

May 12, 1999



LONG TERM CARE SERVICES
of VENTURA COUNTY, INC.

May 10, 1999

Consumer Consortium on Assisted Living
PO Box 3375
Arlington, VA 22202
Attn: Rhonda Buckner

Re: Assisted Living Quality-of-Care and Consumer Protection Issues

Dear Rhonda:

I understand that this letter will be part of written testimony for the Senate Subcommittee on Aging regarding the above-mentioned subject.

As State Certified Ombudsmen in California we have found several flagrant violations that address the following issues:

- 1-Quality of Care
- 2-Discharge Issues
- 3-Contract Issues
- 4-Marketing Issues

1-A resident was found lying on the floor near her bed in the morning. She had aspirated her vomitus and it had dried on her face and in her hair. This indicated that she had been lying in the vomitus for quite some time without staff attention. This facility has over 200 beds. It was reported that the resident could have been on the floor for as long as 8 hours. This resident could not transfer from bed to wheelchair without assistance. However, according to staff, it was not uncommon for her to try and get up on her own and that she would sometimes fall.

The facility had no plan addressing this problem and staff had not been instructed to do anything special to assure that she was protected from falls. The resident frequently used the emergency call system. At the time of this incident a staff member had tied the cord to the activation device so that the resident could not reach it. No one admitted doing this, however, some staff members had observed the cord tied out of reach.

Upon arrival at the hospital resident was diagnosed with respiratory failure secondary to aspiration pneumonia. Resident subsequently died at the hospital.

Upon investigation, night staff member could not be certain if she had changed the resident at 6:00AM. There is supposed to be written documentation of this. However, two weeks of those records were conspicuously missing. In addition, the account of events that occurred during the night by one staff member was inconsistent with those of other staff member.

2-During a two year period one 6 bed facility was cited 10 times for inability to communicate with residents in English. Daily menus were posted in Polish. Every facility is required by law to have one English speaking staff member on duty 24 hours a day.

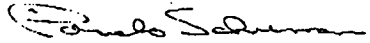
3-A large facility's glossy brochures (enclosed) offer "menus designed and approved by a staff nutritionist and dietician to ensure nutritive value, quality, variety and appeal". A resident confronted the cook with the fact that corn dogs and potato chips, bologna sandwiches and peanut butter and jelly were not nourishing and that the residents needed fresh fruits and vegetables and decent cuts of meat other than frozen codfish. The cook responded to the resident that the menus came from the corporate office and he could not alter them. Further, he stated that he was allotted \$1.33 per resident per day for food. Recently residents were served noodle soup(starch), canned ravioli (starch), canned corn (starch), mashed potatoes (starch), and one dried inedible pork chop.

4-A resident developed pneumonia, hypernatremia renal failure, dehydration and incontinence while in the care of a facility. All conditions were due to obvious neglect. Resident was hospitalized and the facility discharged the resident without refund even though the conditions developed due to the neglect of the facility.

I hope this information responds to some of the issues you wish to cover. We have many more examples of abuse, neglect and fraud by residential care facilities. I strongly believe that without the presence of the Ombudsman in these facilities the problems would go completely unnoticed.

In closing I would like to quote one of our Ombudsman, "It is beginning to occur to me that I will never successfully solve all the problems with which I am confronted. My avowed ambition to leave this world a little bit better than when I joined it is being constantly thwarted by people's insistence on developing new problems." With your help, perhaps we can solve these problems together.

Cordially,



Pamela Schuman, Executive Director



May 4, 1999

The Honorable Charles Grassley
Chairman, Senate Special Committee on Aging
United States Senate
Hart Senate Office Building, Room 135
Washington, DC 20510

The Honorable John Breaux
Ranking Member, Senate Special Committee on Aging
United States Senate
Hart Senate Office Building, Room 516
Washington, DC 20510

Dear Chairman Grassley and Senator Breaux:

Thank you for giving our Chairman, Philip J. Downey, the opportunity to testify on behalf of the purpose-built, professionally owned and managed seniors housing industry at the April 26th Senate Special Committee on Aging hearing on assisted living. Because the American Seniors Housing Association was not given the opportunity to review the GAO report (*Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States*) prior to the submission of our written testimony, we would like to comment on this report and highlight what we believe are several flaws in the study.

After examining the GAO report, we believe that it provides an inaccurate portrayal of the assisted living industry. While we are not suggesting that the industry is problem-free, we believe the GAO report contains a significant number of errors that prevent it from serving as an authoritative examination of the assisted living industry.

There are five specific concerns that we would like to bring to your attention.

1) The report indicates that the sample of assisted living residences in the GAO survey was extremely varied – from two beds to over 600 residents. Forty percent of the residences participated in Medicaid or other public assistance programs. Since the GAO's witness, Kathryn Allen, Associate Director, Health Financing and Systems Issues, testified that the study found problems in all segments of the sample, we would like to examine the cross-tabulated data that allowed her to reach this conclusion. While the GAO, following generally accepted research practices, presumably examined findings based on dozens of different sample segmentations, we would be pleased to analyze the findings on the basis of the following three characteristics: (a) residence size; (b) licensure classification; and (c) payment source (i.e. whether the residence receives payment from public funding sources, such as Medicaid or SSI).

2) As the GAO itself notes, "most residents pay for assisted living out of pocket or through other private funding." ASHA has examined all known public data on assisted living by payment source and has concluded that approximately 10 percent of residents nationally residing in purpose-built assisted living receive public assistance. The fact that 40 percent of the GAO sample includes

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residences that participate in public funding, through either Medicaid or SSI, raises serious questions about whether the findings are reflective of assisted living, as the GAO contends, or are instead more reflective of "board and care" homes which have a long history of quality of care problems and significant participation in public funding programs.

The high participation of publicly reimbursed "assisted living" residences is even more questionable in light of the fact that roughly half of all Medicaid beneficiaries nationwide in assisted living live in a state (North Carolina) that was not among the four states studied by the GAO. Additionally, two of the states included in the GAO study (California and Ohio) do not provide Medicaid or state assistance for assisted living. Is this report representing "assisted living" findings or is it more accurate to conclude that this is a study of "board and care" with some assisted living?

3) There are also troubling aspects of the GAO research methodology. For example, the GAO surveyed 955 randomly selected facilities and received 721 responses. The report states that 99 of these surveys were excluded (14 percent) because the respondents did not provide assisted living services. The GAO then randomly selected another 753 of the original 955 assisted living residences who received the survey to determine the extent of quality problems. However, when the GAO followed up with state licensing agencies, ombudsmen, and other state officials, they failed to eliminate the 99 settings that do not provide assisted living services. Thus, it is statistically possible that 131 (14 percent of the original sample of 955) of the 753 "follow-up facilities" used to determine the report's findings on quality care may not even provide assisted living services. Why did the GAO fail to eliminate non-assisted living residences from their examination of quality when they did so in their survey related to consumer information and services?

4) Another concern about the GAO report relates to how the agency gathered information regarding quality problems in assisted living settings. The GAO acknowledges on pages 35 and 36 that it could not eliminate "double-counting" of reported quality problems because of agency data limitations. This flaw is most troubling since nearly one-third (30.1 percent) of the complaints about quality in the report were generated by agencies required to refer unresolved complaints to the licensing agency – guaranteeing that all unresolved complaints found by either the ombudsmen or adult protective services would be double-counted. Nearly half (45 percent or 825 of the 1,846) of the complaints reported by each state's licensing agency may have been counted twice. Given the enormous limitations of this data, why was this information included in the final report?

5) Data presented in the body of the report is inconsistent when compared to the data presented in the Appendix in instances that were highlighted extensively during the Committee's hearing on April 26, 1999:

a) Table 5 (page 15) in the report states that 78 percent of the facilities surveyed provide written descriptions of services included in the basic rate. However, data on page 46 (Question 18 Part A (a) and B (a)) indicate that 97.3 percent provide such written materials to potential residents and their families. For reasons that are unclear, every data point provided in Table 5 with regard to written information provided to prospective residents is inconsistent and under-represents corresponding data presented on page 46.

b) The report states on page 15 that "only one out of four of the facilities we surveyed

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indicated that they routinely provide a copy of the contract to consumers before they make their decision to apply for admission." Data presented on page 46 (Question 18, part A (a), B (a) and C (a)), however, clearly indicates that 84.5 percent (525 out of 621 respondents) of providers surveyed indicate that they usually provide the resident agreement or contract to potential residents and their families.

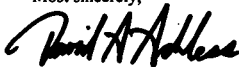
c) A very similar question regarding resident agreements or contracts was asked in the GAO survey (Question 20). As noted on page 47, 87.9 percent of respondents said they provide the contract to interested parties, both routinely and upon request. It is unfortunate that the GAO in their presentation of survey findings and verbal testimony before the Committee focused on the assertion that just one-quarter of assisted living providers give "all interested parties" a copy of the contract. The data does not support this assertion.

The survey respondents likely interpreted the term "all interested parties" differently than "prospective residents" and answered questions 18 and 20 as one might have expected. Resident agreements or contracts are often 20 to 30 pages long and are not usually given to anyone who walks into an assisted living residence and requests "information." The majority of prospective residents and their families often visit assisted living residences multiple times prior to making a decision to move. Formal contracts are generally not distributed to "interested parties" at the initial visit, but rather to "prospective residents" who indicate they are seriously considering an assisted living residence.

The American Seniors Housing Association believes that it is the primary responsibility of all assisted living providers to offer consumers and their families complete and accurate information. It is also crucial that the health, safety and welfare of assisted living residents be the number one priority for all persons involved in the shelter and care of our nation's elderly.

We appreciate the Committee's work and respectfully request that this correspondence be made part of the hearing record. We look forward to working with you and your staff in the near future.

Most sincerely,



David S. Schless
Executive Director

cc: Richard L. Hembra, Assistant Comptroller General, General Accounting Office, Health Education and Human Services Division

RESPONSES TO QUESTIONS RAISED BY THE AMERICAN SENIORS HOUSING ASSOCIATION ON GAO'S REPORT AND TESTIMONY ON ASSISTED LIVING FACILITIES¹

STRATIFICATION OF QUALITY-OF-CARE AND CONSUMER PROTECTION DATA

1. *Question.* During the Senate Special Committee on Aging's April 26, 1999 hearing, the GAO witness testified that "the study found problems in all segments of the sample." Can GAO provide cross-tabulated problem data by (a) residence size, (b) licensure classification, and (c) payment source?

Answer. As agreed with our congressional requestors, our study objectives were to describe residents' needs, facility services, consumer information, and the type and frequency of quality of care and consumer protection problems for a sample of assisted living facilities in four states. The objectives did not include determining whether the type or frequency of problems varied by facility characteristics, such as residence size, licensure classification, or payment source. Nevertheless, as we stated in our testimony, quality-of care and consumer protection problems existed in all sizes and types of facilities.

The 16 examples of quality of care and consumer protection problems cited in our report occurred in 14 different facilities of varying sizes and types. They were distributed across all four states—6 from Oregon, 5 from Florida, 2 from California, and one from Ohio. All 14 were licensed in their states—11 as assisted living in Oregon and Florida, 2 as residential care facilities for the elderly in California, and 1 as a residential care facility in Ohio. Additional information on facility characteristics is available for eleven of these 14 facilities that responded to our facility survey and indicated they were a provider of assisted living. These 11 facilities ranged in size from 9 to 180 beds, with a mean of 82 and median of 75. Ten were for-profit facilities and one was non-profit; six received some public funds while five were private pay only; and five were part of a corporation that owns or operates more than one assisted living facility while six were individually owned.

USE OF PUBLIC ASSISTANCE BY RESIDENTS OF ASSISTED LIVING FACILITIES

2. *Question.* The GAO report states that 40 percent of facilities responding to its survey accept Medicaid or other public funding. However, studies have shown that nationally only 10 percent of assisted living residents receive public assistance. Does this difference raise questions about whether the report's findings are reflective of assisted living or are instead more reflective of board and care facilities that have a long history of quality of care problems and significant participation in public funding programs?

Answer. The distinction to be made here is between "facilities" and "residents." As noted in our report, 40 percent of facilities reported they receive Medicaid or other public funding to care for one or more residents. Our findings relate only to the percentage of facilities that accept any publicly supported residents, not to the percentage of residents actually receiving a public subsidy. Florida and Oregon have made use of Medicaid waivers to help pay for assisted living, and this is reflected in the proportion of facilities that accept public funding in these two states—43 percent in Florida and 86 percent in Oregon. In contrast, the percentage of facilities that accept public funding in California and Ohio was 28 and 27 percent respectively, primarily from SSI or state supplements. Furthermore, while the Florida assisted living category includes some small facilities that might be considered "board and care," most assisted living facilities in Oregon are medium or large-sized, purpose-built, professionally owned and managed facilities.

SAMPLING METHODOLOGY FOR PROVIDER SURVEY AND STATE DATA ANALYSES

3. *Question.* The methodology section of the GAO report suggests that GAO eliminated 99 non-assisted living residences (14 percent of responses) from its analysis of provider survey data because the respondents indicated they did not provide assisted living services. But these 99 were not excluded from the analysis of state quality of care and consumer protection information. Is it possible that as much as 14 percent of the facilities with quality of care and consumer protection problems did not provide assisted living services?

Answer. No. With only two exceptions, our analysis of 200 facilities with 5 or more quality of care or consumer protection problems did not include facilities that indicated on their survey that they did not provide assisted living. Two Florida fa-

¹ See *Assisted Living: Quality-of-Care and Consumer Protection Issues in Four States* (GAO/HEHS-99-27, April 26, 1999) and *Assisted Living: Quality-of-Care and Consumer Protection Issues* (GAO/T-HEHS-99-111, April 26, 1999).

cilities indicating on their survey that they did not provide assisted living were, according to state records, specifically licensed as assisted living, and were therefore included in our analysis.

Of the 467 facilities that had any quality of care or consumer protection problem, only 14 responded on their survey that they did not provide assisted living services. Six of these 14 facilities were from Florida and were specifically licensed as assisted living. Although the remaining 8 facilities from California and Ohio were not removed from our analysis, they accounted for only 17 of the 4,504 total quality of care and consumer protection problems we reported in Appendix III of the report.

DOUBLE-COUNTING OF QUALITY OF CARE PROBLEMS

4. *Question.* GAO acknowledges that it could not eliminate double counting of reported quality problems because of agency data limitations. Is it possible that the problems identified by ombudsmen and Adult Protective Services (APS), that are required to report problems to licensing agencies, could have been reported twice? ASHA estimates that as many as one-third of the total number of problems could have been reported twice. Given these limitations, why was this data included in the report?

Answer. Our report acknowledged the possibility of some double counting of quality of care and consumer protection problems. While the full extent of double counting could not be determined from the state data we were provided, it is likely to be much less than ASHA agencies to refer problems to the licensing agency; in Oregon, the APS agency generally investigates assisted living complaints on behalf of the licensing agency. Second, most of the quality of care and consumer protection problems cited by state licensing agencies were identified during the facilities' most recent annual licensing survey, not during inspections conducted in response to complaints or referrals from other agencies. Notwithstanding the possible double counting, the state data revealed sufficient numbers of quality of care and consumer protection problems that were serious enough to warrant concern by states and providers, as well as by residents and their families.

CONSISTENCY OF DATA PRESENTED ON CONSUMER INFORMATION

5. *Question.* Can GAO clarify why the data presented in the body of the report regarding written consumer information does not agree with that in the provider survey in Appendix II? Specifically, the data in table 5 of the report regarding the percentage of facilities providing key written information to prospective residents appears to be based on responses to survey question 18. However, the percentages in table 5 differ from those in the survey in Appendix II. In addition, the report states that only one of four facilities routinely provide a copy of the contract to consumers; however, survey question 18 in Appendix II appears to indicate that a much higher percentage of facilities usually provides a copy of the contract to prospective residents and their families.

Answer. The data in table 5 were based on a combined analysis of responses to survey questions 18 and 20. These two questions were designed to indicate whether consumers were receiving written information, particularly the resident agreement or contract, in advance of their deciding to apply for admission. Question 18 of the survey provides a useful indicator of whether various written materials contain certain information. Question 20 asked directly whether the facility routinely provides a copy of the contract to consumers prior to their deciding to apply for admission. In responding to question 20, only one in four (152 of 608) facilities indicated they routinely provide a copy of the contract to prospective residents.

As the note to table 5 on page 15 of the report states, the percentages in the table represent respondents who provide information in writing and, in the case of the contract, in advance of a resident's choosing to apply for admission. Thus, the responses to survey question 18 were adjusted if the respondent indicated that the contract was the only place certain information was contained in writing and they indicated in question 20 that they do not routinely provide a copy of the contract in advance.

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