
Council Meeting

of

NEW JERSEY ADVISORY COUNCIL ON ELDER CARE

“Testimony concerning health care and caregiving for the elderly”

LOCATION: Morris Hall
Lawrenceville, New Jersey

DATE: April 15, 1999
1:00 p.m.

MEMBERS OF COUNCIL PRESENT:

Assemblywoman Carol J. Murphy, Chair
Assemblyman Louis A. Romano
Theresa L. Edelstein
Joanne P. Robinson
Bernice B. Shepard

ALSO PRESENT:

Andrew Aronson
(representing Susan C. Reinhard)

Irene M. McCarthy
Office of Legislative Services
Council Aide



Meeting Recorded and Transcribed by
The Office of Legislative Services, Public Information Office,
Hearing Unit, State House Annex, PO 068, Trenton, New Jersey

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Gerry Cannon, R.N.

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submitted by
Sue Lachenmayr

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ASSEMBLYWOMAN CAROL J. MURPHY (Chair): I want to thank all of you for being here because we truly appreciate it. And while it seems as though your audience is not great in quantity, you have to know that we are the quality folks. (laughter)

Because these meetings are transcribed and recorded, we will have everyone's ears and eyes when it comes time to review this material. So we appreciate you taking time from your day because our process is education, education for ourselves, education then for the people of the state because care for the elderly is a huge concern, and it is us we are talking about taking care of, which makes it even more poignant, if you will, and important to us. So thank you so much for being here.

And Morris Hall is a very lovely facility. We are indebted to those who have made this possible. What a nice place to be today. And thank you for the refreshments, which brighten our tummies and make us smile.

We will be hearing today from assisted-living facilities and programs starting with Kathy Fiery.

One of the issues, clearly, with this-- When the Governor's executive order came out, there were three questions -- I think it's three. They all go together after a while. How do you see yourself living in terms of where you will be living as you move into the what is, I've been told is called, the third age but as you move into the latter number of years you may have? And the second is, if you need care, who do you see as your caregiver? How will you receive that care: in a -- in some sort of sheltering facility or some individual-- And then, if you are going to receive any kind of care, if you are going to have a choice of living options, how are you going to pay for them?

So these are the three questions we have been looking at through all of this. And while we may seem to have strayed from a straight and narrow three questions, everything that we look at rests upon something else that rests upon something else and ends up resting upon how you will live as we move forward. And that's the singular issue that, as a State, we need to help people have a plan for if we are going to help anyone else plan for that. We have to have looked at it, and we have to have devised some support systems and put some systems in place that people can access in order to make their dreams or their thoughts the best reality that we can create. So that's the purpose.

And, Kathy, thank you so much for being here.

KATHY FIERY: I did want to start with thanking Assemblywoman Murphy for inviting us today and, of course, Peggy for all of the arrangements that are never easy and also a thank you to Morris Hall for having us.

We are going to take, roughly, an hour -- a little bit less time because I know that Andy wants to say a few words as well. So I thought that it would be good if I could define for you a little bit of what assisted living is so that, at least, we're on the same page when we're talking about assisted living. And then I'm going to ask the two providers that I have with me today to come up and speak from their experience as providers in the field.

ASSEMBLYWOMAN MURPHY: The microphone is having a little difficulty picking you up clearly, Kathy. So you may have to speak a little louder.

MS. FIERY: Is it on?

ASSEMBLYWOMAN MURPHY: It doesn't amplify.

MS. FIERY: It doesn't amplify. I can scream.

ASSEMBLYWOMAN MURPHY: No, but an authoritative--

MS. FIERY: Not a problem.

If we look at assisted living on a continuum of care -- if we look at all of the services that are available to seniors, we start out on one end of a continuum is independent housing. And that could either be in somebody's home that they've lived in for 25 years, or it could be in an affordable housing unit, but the point is it's independent.

The next step along a continuum and the options available for seniors today would be Class C boarding homes. They provide some limited assistance to individuals living in a more protected environment. Again moving up the scale of the continuum, you would have residential health-care facilities. Those facilities are residential in setting and they provide health-care services. They have nurses on staff. They have to provide extra services to people, meals, housekeeping, those kinds of things.

As you continue along that continuum, the next step would be assisted living, and I'm going to come back to that, of course. And the final step, at this point, is nursing homes. So you can see that assisted living sits on a continuum of options for seniors in this state.

There is another group, that sometimes gets confused with assisted living, which is continuing care retirement communities. And they incorporate independent living as well as sometimes residential health care, sometimes assisted living, and then nursing or long-term care. So they have different options as well on the same campus.

So let me go back to what assisted living is, which is again along that continuum between residential health and nursing.

ASSEMBLYWOMAN MURPHY: Excuse me.

MS. FIERY: Sure.

ASSEMBLYWOMAN MURPHY: Assemblyman Lou Romano has joined us.

ASSEMBLYMAN ROMANO: Excuse me, I apologize for being late, but today is filing day. She is a shoo-in, so she doesn't worry about it.
(laughter)

ASSEMBLYWOMAN MURPHY: We were just finished talking about you because we were all so sure that you would be here.

ASSEMBLYMAN ROMANO: Good or bad.

ASSEMBLYWOMAN MURPHY: You never miss a meeting.

It is nothing but good, Lou.

ASSEMBLYMAN ROMANO: Is she here?

ASSEMBLYWOMAN MURPHY: No, you are sitting right there. Kathy Fiery is speaking now.

MS. NELSON: Did he file?

ASSEMBLYWOMAN MURPHY: Of course he filed.

ASSEMBLYMAN ROMANO: I filed yesterday.

ASSEMBLYWOMAN MURPHY: On which side?

ASSEMBLYMAN ROMANO: I'll talk to you after 4:00 p.m.

ASSEMBLYWOMAN MURPHY: Which side?

ASSEMBLYMAN ROMANO: Democrat. A Republican can't win in Hudson County. (laughter)

ASSEMBLYWOMAN MURPHY: Kathy Fiery from the New Jersey Association of Health Care Facilities, Lou.

Thank you, Kathy. I'm sorry.

ASSEMBLYMAN ROMANO: I apologize for breaking.

MS. FIERY: I was discussing assisted-living. And as we talk about assisted-living, there are a couple of terms that I should cover as well because they're used interchangeably. Assisted-living facilities are facilities that are built specifically for the purpose of providing assisted-living services. What gets confusing is that we also use the words comprehensive personal-care home to describe assisted living. And succinctly, what that is, is a building that has been converted for the purposes of providing assisted living. Many times there are safety issues or fire code issues. They change the rating of the building, in other words, to bring it up to a higher standard for individuals who cannot self evacuate from a building. And those are called comprehensive personal-care homes. They provide assisted-living services. They still have to comply with the same assisted living regulations, but they are a converted building. And then there are assisted-living programs, and that is an assisted-living option that exists within affordable housing. So those are the three different types of assisted-living that we talk about.

ASSEMBLYWOMAN MURPHY: Kathy, may I ask you a question?

MS. FIERY: Certainly.

ASSEMBLYWOMAN MURPHY: Comprehensive personal-care home converted from what?

MS. FIERY: It can be a Class *E* boarding home. More often, they're residential health-care facilities that convert to assisted living, and then they are licensed as comprehensive personal care, but they are assisted living.

ASSEMBLYWOMAN MURPHY: Okay, thank you.

ASSEMBLYMAN ROMANO: What's the third one again, please?

MS. FIERY: Assisted-living programs. And those are assisted-living services that are brought into subsidized housing.

Assisted living itself began in the early 1990s, but the regulations, and let me talk about those, were started in December of 1993. There were no assisted-living buildings, though, until about the mid part of 1994. So I want to focus on that briefly because I think it's important that we understand that this is a very young industry. We haven't worked out all of our issues yet. We don't even know what some of our issues are yet. The point being, it's still young, it's still progressing, and it's changing and moving.

There has been rapid growth in this field however since 1994. And there are approximately 82 licensed buildings that are operating as assisted living or comprehensive personal care. And I just got the new information this morning -- there are about 36,000 beds in the CN process. We don't know how many of those will be built, but they are still in the CN process.

There is a Medicaid waiver that is available to provide funding for individuals who cannot afford to live in assisted living who meet financial criteria as well as medical criteria. There are different levels of reimbursement for the different types of assisted living. Assisted-living programs get reimbursed at \$40 a day, comprehensive personal care gets reimbursed at \$50 a day, and assisted-living residences at \$60 a day. Those are not numbers that were scientifically derived. They were not based on any financial pro formas or anything else, so we do ask and we do believe that those numbers need to be revisited, and we need to look at a reimbursement system that would make

some sense based on some real numbers now -- that we have buildings that are operating.

ASSEMBLYMAN ROMANO: Please allow me to ask this.

MS. FIERY: Sure.

ASSEMBLYMAN ROMANO: You know, when you talk about Medicaid waivers and then you're talking about -- they would pay up to, and then the client is supposed to pay the difference, am I correct?

MS. FIERY: No, the Medicaid waiver pays for the care only, so that reimbursement per day that is paid to the facility is for the resident's care. If that individual also qualifies for SSI, then they would receive -- the individual would receive an SSI payment that they could then pay to the facility.

ASSEMBLYMAN ROMANO: Nothing to the effect that they're eligible for Medicaid, but then they have their own money to pay for extra things? That's not the case?

MS. FIERY: No, they do not pay. If they are Medicaid eligible -- or the Medicaid waiver eligible that's what they pay.

It's important to also note that there are 34 of those licensed providers that have provider numbers and that are willing to accept Medicaid recipients -- 34.

ASSEMBLYWOMAN MURPHY: In the state?

MS. FIERY: Yes, ma'am.

ASSEMBLYWOMAN MURPHY: And how many units would that be -- plus or minus?

MS. FIERY: Oh, goodness. I wouldn't even know.

ASSEMBLYWOMAN MURPHY: Is there any way you could get that information for us, Kathy, and where they're located because that's helpful to us to have a sense of--

MS. FIERY: Yes. Medicaid has all that. I'll get that for you.

It is also important to note that the number of Medicaid slots -- the usage of those slots has doubled in this past year. The waiver has been around for three years, and granted, the usage was slow in the first two, I've been told by Medicaid that that has doubled just in this past year. And we expect that to continue just like we expect to see the number of licensed providers accepting Medicaid to continue to grow. It's been growing since I've been in my position in January, so we've just watched that number grow.

I would also like to say that as an industry, we believe we work very well with the Department of Health and Senior Services, and I'm not saying that just because Andy is sitting in front of me. We believe that to be true for two very important reasons. One of them is that we are in our second set of regulations that come from the Department to us. The first set, as I referenced, began in December of 1993. They expired in December of 1998. We're about to receive our second generation of regulations. They are not significantly different from the first set of regulations, and that says to us, as providers, that the Department is still willing to work with us as providers to make this experiment, if you will, that we call assisted living work. It also says that we as providers are still doing some things properly, which is why the Department has not had to respond to us with increased regulations. So that is a very positive sign.

And also, just this morning, we had our assisted living work group meeting, which is a group that, until very recently but has started again, meets routinely with providers, with consultants in assisted-living -- and with the Department as well as people from Medicaid, etc. And it gives all of us an opportunity to tell each other how we feel. The providers get to tell the Department what is working and what is not working. The Department gets to tell us what they're concerned about, what they're seeing out in the field, what we need to be prepared for in terms of education and training, etc. And we find that environment to be unique and very positive in the sense that it is free flowing information back and forth, and it can only serve to strengthen assisted living as it continues to grow. We do not need more assisted-living regulation, and we certainly do not need Federal regulation. And we as providers work very hard to make sure that we don't get that. And we try very hard to make good, positive decisions for residents so that we don't have that.

Assisted living is based on choice and dignity, independence, individuality, and privacy, all allowing aging in place in a home-like setting. And the definitions that you would bring to those words are really consistent with what assisted living believes they are. What I'm saying is common sense is what helps assisted living such a reasonable option and a reasonable way to take care of people. What we really need to be able to do in this field is continue to attract intelligent, dedicated providers so that we can continue to make good choices so that we can continue to work cooperatively with the Department as well as the consumers, and we can continue to grow this industry the way we all envisioned it way back in the early 1990s.

At this point, I would like to turn it over to my providers so that they can tell you what it's like every single day to do this.

First, I would like Gerry Cannon from Hospicomm to come and talk to you. And I promised them I would present their credentials to you, so they wouldn't have to do that. Gerry is an R.N. and has a BS. She has 34 years in health care. The last of -- 16 years of which have been in the long-term care industry. She is certified as an assisted-living administrator. She is certified in quality assurance, and she is an DON case manager. She currently works as a corporate consultant and a QA nurse for Hospicomm, which is a developer and manager of nursing homes, assisted living, comprehensive personal care, and adult medical day care. This is also very interesting. She is in the middle of her master's degree in health services administration, where her thesis is the development of curriculum for medical students about care alternatives and long-term care. She is also working on a textbook for the same and a book for the consumer on that same topic.

ASSEMBLYWOMAN MURPHY: Wow.

We've been talking about you. We just didn't know your name, but we've been doing a lot of talking about better education for the medical profession in terms of the elderly and their needs.

Thank you very much.

GERRY CANNON, R.N.: The idea of talking to medical students, of course, is education -- that hopefully, by the time they become real physicians that they will understand all of the care alternatives for the elderly.

As Kathy said, assisted living is a care alternative, and it has values -- philosophy, but it has values. We use those values every day when we make

sure that the folks in our household or ourselves are clothed and dressed and fed. That's daily activities -- the daily activities of living. When we see to their social needs, getting to doctor's appointments -- how many baseball and football fields can you be on at the same time and get somebody to piano practice? That's the social aspect of it. And assisted living helps the elderly with both their activities of daily living and their social needs.

We believe in keeping them as independent as long as possible. We need assistance with our independence every day. We rely on our organizers, our secretaries, ourselves, so we still need that assistance, and the elderly need it also. If we believe that they should remain independent for as long as possible, then we can like assisted living, and we should like it. If we believe that the elderly should be in a safe and secure environment free from worry, shoveling snow, mowing the lawn, climbing on ladders to change light bulbs and fix curtains, and etc., we will like assisted living.

Those activities that I just mentioned are very risky for anybody but especially for the elderly. And they account for more than half of the statistics of home accidents. And those accidents result in serious or permanent injury, sometimes even death. So assisted living is a better solution. Another set of grim numbers: the amount of elderly, and we hear it on the radio, that are conned out of their money every day -- they're scammed. They're living at home, barricaded because they're afraid of being robbed or murdered. They're vulnerable. Assisted living is a better solution.

Depression in the elderly is fast becoming the No. 1 diagnosis because they are lonely, they have a loss of independence, they have a loss of social contact, they have a loss of their own physical function, and no one to

encourage them to keep on going, no one to help them with their social aspect and contacts. So depression becomes a big factor in the elderly that is just really being recognized by the medical community.

Assisted living is the better solution because it promotes independence, social contact. It still keeps them thinking of themselves as worthy individuals. A lot of times, they lose their worthwhile feeling. "I'm no good to anybody. I'm just a burden." And assisted living plays down that aspect of it.

If you like assisted-living for those ideas, you'll like assisted-living for what it isn't. It isn't an institution. Assisted living is a philosophy with a set of values that is practiced by caregivers and providers every day. We believe in the individuality of the person and keeping their independence going. Assisted living isn't a building. Building is important. We need more of them. We want more providers to give us those buildings. There is an old saying, "It's what's inside that counts," and that's the assisted-living philosophy values programs itself. Even with comprehensive personal-care conversions, the assisted-living philosophy is there. We see many abandoned schools, factories, and warehouses being converted, which is great because it provides more buildings, but it's inside that counts.

We need more of those buildings. However, sometimes the local neighborhoods get a little skeptical when you want to put something new inside the neighborhood, "Not in my backyard." But the public needs to be educated. What is assisted living, who is it serving, and what is its purpose? And we also have to educate the local townspeople that, sometime in the future, they too may need to take advantage of assisted living. So, as

important members of the community, we would hope that you would turn and educate your neighborhoods about assisted living.

A little food for thought. Think of a place where you could provide services for the elderly. It could be a room, your apartment, your house, and you're going to have the elderly there. You're going to give them three meals a day, unlimited access to the refrigerator, provide security, social recreational, nursing, and medical services -- some cases -- sometimes transportation. Of course, you're going to throw in heat, air-conditioning, electricity, water, and you're going to do it all for \$1.50 a day.

Kathy eluded to the Medicaid reimbursement. When you even it out, it's \$1.50 a day. We want providers. We want providers to have services for these folks. One dollar and fifty cents a day is not going to pay bills. It's certainly not going to pay medical bills or nursing services. You know your own household doesn't run on \$1.50 a day. So we need to educate people about why the reimbursement needs to be just increased to provide ample services. We would have more Medicaid people being able to take advantage of assisted-living -- those folks that really need to take advantage of assisted-living and comprehensive personal care if they were able to have more of an allotment.

ASSEMBLYMAN ROMANO: Excuse me, what does the \$1.50 represent? I mean, when you use that number--

MS. CANNON: Fifty dollars a month. As Kathy said, there is a tier; it is \$40, \$50, or \$60. I took the mean average of \$50. And it works out to \$1.50 a day, which isn't much to give them for their medical services. Even if you add it to their SSI, it's not a lot.

ASSEMBLYMAN ROMANO: Is that what the Medicaid waiver is? I mean, is this Medicaid paying this?

MS. CANNON: Yes. It's not an entitlement program, it's an allotment that's added to the SSI.

MS. EDELSTEIN: Excuse me, Carol.

My understanding is that the \$60, \$50, and \$40 are pre diems, not monthly.

MS. CANNON: Wrong representation. It's still not a lot of money to take care of people.

ASSEMBLYWOMAN MURPHY: And that's-- The dollars become incredible issues.

MS. CANNON: Right.

ASSEMBLYWOMAN MURPHY: That \$40, \$50, or \$60 is for care only. So it is not for the physical facility.

MS. CANNON: Right.

ASSEMBLYWOMAN MURPHY: It is for the services that are received.

MS. CANNON: Right, for the medical nursing services -- for their taking care of them. But at the same time, you still have to provide these other services. So it still does not come out to a lot of money to provide for everything that these folks need.

The big three, and I'm not talking about the cars -- the car guys, I'm talking about science and medicine and technology. They're very helpful in that they're eliminating a lot of diseases, which means everybody's healthier and living longer. It's projected, and the numbers vary, by the year 2010 that

there will be 4 million-plus people over the age of 65 years old, which is amazing, and more amazing is, what's going to happen in the future? Where are we going to house these folks? How are we going to take care of them.

In 20 or 30 years, when you turn 70, are you still going to be shoveling snow or mowing the grass or worried about those things, or are you going to have an assisted-living or a comprehensive personal-care program that you're going to be able to turn to?

Assisted living for the elderly is a better solution. When the future becomes the present, will we be able to take advantage of those programs, will they be there for us? Assisted living is a better care alternative, it's a better solution for the elderly, and it is a care alternative that they can take advantage of. Assisted living is a great concept for today. For tomorrow it's going to be a necessity.

MS. ROBINSON: Gerry, can I ask you a question?

What level of function do residents need to be at in order to be supported in assisted living, and what is the staffing like?

MS. CANNON: Is Kathy going to take-- I think Kathy is going to take care of that, and she'll be able to go into that and that will vary.

KATHY RYAN: Kathy is a common name today.

ASSEMBLYWOMAN MURPHY: Thank you.

MS. RYAN: I'm Kathy Ryan. I've had the pleasure of running an assisted-living facility now for two years, and it is a real joy. It is not something I will ever receive a Nobel Prize for or make a million dollars for, but it is the opportunity to make a real difference in seniors' lives every day. When staff first come in, they don't quite understand that, but since

February, we've lost 10 residents to death. And it drives home the point that that extra five minutes you spend in the morning saying hello, that cup of tea, the shower you give them -- it can be their very last interaction.

One lady came to us and she was very taken -- her hair had been a mess, and her grandkids were coming, and so she needed a shower and her hair done. We could wash it, but she wanted the hair dresser. And I was so thrilled that on Friday she had her hair done. And I sat and had -- she had a cocktail and I had a tonic at our cocktail hour in the afternoon, and she just raved about how well she looked and how good she felt and her kids were coming. And I got called on Saturday that she had a heart attack and died that night, but she had seen the grandkids. And it drives home that this is the business we're in.

The residents that come to us, are they thrilled? No. They're dealing with aging. They're dealing with the hardest thing, probably, any of us has to do. They've lost their support systems, their spouses died, their friends are dying, they're dealing with the fact that their health is not something that's guaranteed. They're not feeling so vulnerable -- or so invulnerable as the youth of today are. They realize that there might not be a lot of tomorrows. Their independence-- The people who come to me are not people who chose to go to retirement centers. They're people who said, "I'm going out of here in a box. I'm living my life here." And now they've reached a point in their life where they're not able to be 100 percent independent. They still cherish the independence, they still cherish their role as adults. They don't want the world to pacify them and look at them as if they're not capable.

What do we do in assisted living? We create an environment where they can be adults, and the limitations that the natural aging process push on them, we help them deal with. Their hearing isn't as good. We understand sometimes that to cover, they say inappropriate things. It's not that their brains aren't working, it's that they haven't heard you. Their eyesight-- People who have dressed meticulously all of their life now have spots on them. We make sure they don't go out that way.

We have a judge who is 96 years old. God bless him, he's as sharp as can be. His speech is a little slower, his tone doesn't project as well as he used to, and due to Parkinson's, he shakes a little bit. So what do we do? We don't give him a shower first thing in the morning, we let him come down in his casual clothes. And after breakfast, we give him a shower and get his suit on. So when he goes to the office, he looks dapper.

Phil came to us. His daughters brought him to us because he was back and forth to the hospital. He is 83 years old, and he was having various medical situations but very, very social. They chose the Chelsea because we were close to his social environment, and they wanted the friends to come back because they knew that if we took the social out of this man he would die.

So one day, I went into the tearoom and I saw him and I said, "Boy, hot date tonight? You look good." He said, "My friends are coming to take me for lunch." He said, "Come here. Could you walk behind me down the hall? I had a problem with incontinence, could you check to see if my diaper shows?" He said, "I'd hate to be embarrassed." So I walked behind him and said, "No one can see it, can hear it. You're fine." And when his friends came and took him out I thought, "We did it. We were successful once again."

What were we successful in? We were successful in creating an environment where his worth was not diminished because his bladder and bowel are not working properly.

Another lady taught me something else that's been very important. She came-- She was a professional lady. Her name was Priscilla. She came to visit her relatives for the holidays. She had a problem with her legs; she was a brittle diabetic. Complications set in, and she ended up losing her leg. They admitted her to the hospital -- a rehab center. By the time she came to us she was walking. I always talk to the residents because that's how you learn everything. "How did you get from there to here? How did you survive this?" She said, "Kathy, losing my leg wasn't the worse thing to happen to me. Losing my sense of myself--" She said, "All these medical people, so well intentioned, come in and tell me what tests -- they don't tell me the tests, they take me to the tests, they give me medicine, but they don't bother to tell me. They select a rehab center, they select all this." She said, "The leg-- I could get another leg, but I had to fight so hard to get a sense of myself."

In assisted living, we give them choice. When I opened and people would come through -- especially the medical community-- "Well, what do you mean you're not a medical diet -- what do you mean you're giving them alcohol in the afternoon?" And I said, "Do you have a doctor's order for a drink? I don't. They have choice." And I bet you everybody in this room makes bad choices, and I bet we enjoy them sometimes. Let's not take their choices away from them. They're only a little older than we are. That's it. They have great wisdom, but we are so busy protecting them we take away their life.

One son was very concerned because his mother kept falling. “Oh, my God, you got to get her in her chair, and you can’t have her walk around. She’s going to fall and break her hip.” And she wrote him a letter. She said, “Dear Paul, your love for me just makes my heart so warm. But let me just tell you another view. When you were a baby and started to take your first steps, I just paused because I knew you had to fall, and I hoped you wouldn’t get hurt.” She said, “Then you wanted to ride the tricycle, and you wanted those training wheels off. And as I’m running down the street with you, holding onto the back, I let go, and I thought, ‘Oh, dear Lord, don’t let him really fall too hard.’ Then 16 years old came, and you drove your car.” She said, “I took those Rosary beads out.” She said, “I’d say goodbye to you, and I prayed the whole time that you’d come home safe and sound.” She said, “Now I’m 89 years old, and yes, I am going to fall. And you want to put me in a chair to keep me safe. What would have happened if I kept you safe? Give me the chance to live my life, and if I fall, I fall.” So we give them choices, they choose.

We intervene if it’s going to be a very dangerous choice, of course. But then again we treat them like adults, and that’s the key. Anytime something happens -- and lot’s. We’ve been open two years, and we’ve had four bomb scares, we’ve had theft. I call a community meeting. I don’t protect them, they’re adults. “We’ve had some thievery going on here. We have a thief, and I don’t know what to do about it. This is what my thoughts are, what are your thoughts?” Because I want a say in my life, and I think they have the right for say in their life. That’s what assisted living is all about. It’s giving them the opportunity to be seniors -- giving them the choice.

Aaron came back from the hospital. He was one of the most gentle and kind men. He was only with us for six months. He had congestive heart failure. He came back, and we were setting up -- there was a Fanwood Day, a festival within our town -- running back forth. And I see him watching all the commotion. I said, "Aaron, don't you want to come down?" He said, "I can't walk that far anymore." I said, "So we have this thing called a wheelchair. We'll put you in and down we'll go." We went down and he had a wonderful time. And, of course, I'm thinking, "The sun is too harsh, you're 92 years old, this is not so good for you." He said, "I'm having a good time."

He stayed for six hours. Our director of billing services, who is almost a senior himself-- In fact, for the first three months, the seniors thought he was part of them. He went out and bought everybody hot dogs and sodas, and Aaron had just this wonderful time. And three days later, I was with Aaron upstairs when we called the rescue squad. He wasn't breathing real well. And as I went down on the elevator with him, he just grabbed my hand so hard, and he looked up and he said, "Thank you for Saturday. It was so wonderful. I just hope I get one more." He never did get another, but he was happy.

It is taking those moments-- When I was in college, there were all these kids who were into Zen. I wasn't that sophisticated then, but, boy, I've learned so much. Take the moment. And that's what we do at the Chelsea. We take every moment because it may be their last. But we're not putting them in a medical model. I've worked in long-term care, and it is a wonderful place, and it deals with a wonderful population, but they're keeping them too safe. We're giving them life with all the different levels of complications it has.

My daughter worked for us. She's a college student. She filled in at the reception desk. She could overhear their conversations, and she said to me, "Mom, they're just like us." I said, "Yes. They love, they're scared, they're happy, they cry. And sometimes they have to be confronted because they're really out of line. They are people."

I really hope, when I'm to the point where I need a little assistance, that I have a place to go where they're going to see Kathy Ryan for Kathy Ryan. And when they come in, they're not going to judge my life by that, but they'll love it by the quality, they'll love it by the fact that I have a community of people to be with who see me for, hopefully, the wonderful person I am, even if my eyesight isn't so good and I don't hear so well and I ambulate a little slower and my bowel and bladder don't activate at the right time and the right place and maybe my I get out of breath when I walk, but I'm still a wonderful human being, and I need to live life to the very last moment.

ASSEMBLYWOMAN MURPHY: Thank you, Kathy, very much. Kathy, can I ask you some questions?

You've described, kind of, the philosophy with which your facility is operational. Is there an assisted-living philosophy in the sense of letting people risk their risks and make their choices? Is that a kind of universal--

MS. RYAN: It is. It's your choice. It's giving people choice. It's maintaining their dignity. It's acknowledging their individuality. Not every 16-year-old is the same, not every 96-year-old is the same.

ASSEMBLYWOMAN MURPHY: Is that sort of a universal basis of the philosophy of assisted-living facilities?

MS. RYAN: It is.

ASSEMBLYWOMAN MURPHY: What is the average daily cost, roughly, on an open-ended thing, for an assisted-living facility?

MS. RYAN: It would really depend on the facility. You can do it for a variety of prices. You probably have them anywhere from \$90 a day to \$130 a day.

ASSEMBLYWOMAN MURPHY: As much as you want.

MS. RYAN: Correct. What usually there is, is a basic price, and then there is an escalating scale for how much assistance somebody needs. We have a basic package that gives you your apartment, your three meals a day, your housekeeping, your laundry, medication reminders, recreation, and availability of staff 24 hours a day. And then we have a point system. We have two levels of care as they age in place.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. RYAN: You're welcome.

MS. ROBINSON: I still have my questions left.

I'm still looking to identify the population that assisted living best serves. Is it just choice, people who really want that kind of environment despite their level of function, or are there limits to what you can support in the assisted-living environment? And then I'm also interested in what kind of support services can clients expect to receive.

MS. RYAN: We have three criteria for people coming in, and maybe this will help you. One criteria is that they're alert enough that they can press an emergency pendant that we have because again these people are in apartments, their doors are locked, you're not walking up and down with the doors open. So it's that they have the ability to be able to seek help. Two,

that they're not wanderers. This is in my assisted-living proper. I do have a dementia unit that I'll talk about. And, three, that they're initially independent of transfer. And that was that they can be wheelchair bound, but they can transfer themselves onto toilet and back. That came from the fact that from being in a nursing center, one of the biggest complaints is that when a senior decides they have to go to the bathroom, the physical aspect is already taking place, so you want them to be able to have that ability when they first come in.

What we've seen with the aging in place-- I think my trickiest thing, in accepting someone in, is their cognitive ability. You can judge a lot of abilities with blood pressure machines and this and that. Cognitive abilities, people cover very, very well, and we need to bring them in when they have enough cognition to learn our building. Then we can cue them for lunch, we can cue them for dinner, we do their showers, we can dress them, we can give them their medication.

After we were open three or four months, we realized that we were able to deal with people as they age physically but not cognitively. So what we did was we took part of our building and we turned it into a dementia unit. It's a secured unit where we expect to dress everybody and feed everybody. I shouldn't say dress everybody, assist them. Some people need to be dressed, some just need to be assisted.

Staffingwise-- How long we can keep people? I've had people die in my building. If I know that they're going to be hospice, they can die with us. One lady now is near blind, and she asked me, probably three times a

week, “When I’m blind, you’re not going to kick me out, are you?” I said, “I would never do that.” No, we will provide assistance.

When I can’t handle somebody, probably, is when they need 24-hour nursing care. There’s eight criteria when you can discharge somebody. You don’t have to. Every case is looked at individually. These become our family members. This is their home. You really don’t want to discharge them if you don’t have to. There are times when families feel that they want to have a little bit more -- they want the medical -- they feel safer with the medical-- But we handle them as long as we possibly can. Statistics-wise, 85 percent of the people in assisted living will stay in assisted living until they die.

MS. ROBINSON: Are there minimum staffing requirements, R.N.s or L.P.N.s or--

MS. RYAN: An R.N. is supposed to be on call. The R.N. lives at our building so much of the time-- An R.N. must be on call, and you have resident attendants. In assisted living, the resident attendants, who are your certified nursing assistants or your home health aides-- They can also go through a 30-hour training course with the supervision of the nurse and also a test by the State. And they then can be taught to give medications. They have a very, very high role in assisted-living. They are really empowered to do quite a bit.

The staffing again-- It’s one of the things that we try to be very careful of to keep our -- to meet the needs of our people and not to overstaff. So what we do is we have busy times. From 7:00 in the morning to 11:00 is our real busy time. From 5:00 p.m. to 9:00 p.m. is our busy time. During the middle of the day, my people don’t need much help. They have a pendant

they ring when the need it. For the most part, they really don't. So you're just wise with what you do. We also use their Medicare benefits. When someone comes back from the hospital, we utilize the visiting nurses, the physical therapists, the occupational therapists. We hook them up with a lot of services.

Depression -- Gerry brought that up. Depression is a major, major issue, so we brought in a nurse-practitioner who is a Medicare-certified nurse. And we had her speak to our whole congregation about everyday losses. What's it like? If you're sitting in my building, you've lost something. You've lost your home, you've lost some sense of independence. But that is a service that we provide. So we don't do all the medical services ourselves, but we're the care manager. We make sure that we hook them up.

One lady came to us, and she was this little tiny thing, and she was not doing well at all. We hooked her up with a dentist to give her dentures, so she could chew. We hooked her up with hearing aids, so she could hear. We gave her some glasses, so she could see better. She had stopped eating all together. We had somebody going in that room every two hours to give her a little bit to give her enough food. We ended up having to get her into the hospital. She had a feeding tube for three months. She's now outgrown everything. She no longer has a feeding tube. She's eating.

But sometimes you just have to hook them up. They're in the community. And to them, living in the community was everything. But they've gotten isolated, and they've just started to come apart, I'm afraid. So when you have something like that and you can bring them back to life, it's a good feeling.

MS. ROBINSON: Just one more question.

Are there required numbers of resident assistants per number of residents or--

MS. RYAN: One thing in assisted living, which has been nice, is our regulations have given us the ability to use our heads. It is not mandated that for every number of people, you have to have a number of attendants. They have asked us to be able to meet the needs of the people. At one point, I could have 68 people and need 25 attendants. As my people age, I might need 35 attendants. As those people die and I take in a new group, I might go back to 22. I must staff in order to meet the needs of the people I have there. The minimum requirement at night is that you must have two people in a building. And that sounds horrendous. Two people in a building with 68 people, what type of care can you give?

However, we all have to have our methods of monitoring, and I have a little computer that registers every call that comes in. From 12:00 a.m. to 5:00 a.m., I average two to maybe three calls a night. My biggest thing is keeping those night people busy. Who knows, down the road, if I have people who get sicker, maybe I'll need other things, but right now my staffing does vary according to the need level of the people who I presently have in my building. As I say, we've lost 10 since February, so you can see that I have a changing population.

ASSEMBLYWOMAN MURPHY: How do you determine the person who will deliver the hospice within your facility? Do you contract with a hospice organization or do they?

MS. RYAN: We are the home. The family really will decide which hospice. We will help them. We will sit with them, and we will say, "These might be the hospices in the area." But again we're in a partnership with the resident, their family, and ourselves, but they are the ones who will make the decision.

ASSEMBLYWOMAN MURPHY: They will contract themselves with the hospice agency.

Thank you.

MS. RYAN: Thank you very much.

ASSEMBLYMAN ROMANO: Madam Chair, I hope you will allow me to say this.

ASSEMBLYWOMAN MURPHY: I will allow you to say almost--

ASSEMBLYMAN ROMANO: We have so much that we hear, and it's all so informative and important.

Let me ask a question. I know that the State produces a list of nursing homes with some sort of approval rating, etc. Now, this may be out already, I don't know of it, but is there any sort of a document that covers the complete purview -- let's say, for example, keep them at home being one? How one can keep somebody at home? And then the next step is types of living arrangements outside the home. And you can have a menu, maybe as long as this table, where you could explain, briefly, just in highlight, perhaps with pamphlets to back up the particular area, or if this was in a pamphlet, you would have one is this, and two is that, and three -- so that people would be able to sit down and make a decision -- or the family can make a decision.

And more importantly, we come to the care manager. How do we make a care manager available when somebody is looking for that decision to make? I know we have the Division of Aging. I know they have people out there, but how do we guarantee or make public again -- make it known how someone can have a care manager come in and sit with the family or the elderly person to go through the entire situation as to what's best for them?

Do you remember we had the discussion, you and I, as trained caregivers -- when we have a constituent-- We, in our own way, discussed several topics to try to determine who this person is talking to me.

ASSEMBLYWOMAN MURPHY: I'm going to go to Rick Abrams.

ASSEMBLYMAN ROMANO: Well, he's a good man. Let's hear what he has to say.

MR. ARONSON: Rick, before you start, let me just say something on behalf of the Department.

What you're talking about, Assemblyman, is basically the whole theory behind New Jersey EASE and what we're trying to develop in this State.

ASSEMBLYMAN ROMANO: I know that, but I didn't know if they took this aspect of it and explored it, amplified it, and made it understandable for the common person.

ASSEMBLYWOMAN MURPHY: But we're talking about New Jersey EASE accessibly through the computer -- the Internet.

MR. ARONSON: Correct.

ASSEMBLYWOMAN MURPHY: Rick.

WILLIAM R. ABRAMS: Assemblywoman Murphy, that's exactly what I was going to say. The whole concept behind-- I think the Department has done a real good and an aggressive job of implementing New Jersey EASE. But that is the whole philosophy. Really, the whole philosophy of one-stop shopping, the whole philosophy of that senior citizen or, certainly as important, their family to come to that area agency on aging to get all of the answers, to get educated, to know what their options are given the condition both medically, psychologically, socially, and financially of their loved ones or themselves.

ASSEMBLYWOMAN MURPHY: And the tool that the New Jersey EASE or the department on aging -- Division on Aging, wherever you do go -- the physical place you end up -- would be to get paper coming from the computer that would list your alternatives and who they are locally and then someone to follow-up on them as a care case manager -- absolutely.

ASSEMBLYMAN ROMANO: But not everybody has a computer.

ASSEMBLYWOMAN MURPHY: I'm just saying that if you went into the department on aging -- if they did, you would go home with paper like this listing your personal kind of things.

ASSEMBLYMAN ROMANO: I'm not suggesting that IDA as the only answer. What I'm suggesting is that the multifaceted approach would have to be senior citizen meetings with someone coming in as good as the speakers who have been here today. I'm not talking about somebody who comes in to speak as a -- how can I put it? -- as an add-on or adjunct or a part-time worker someplace who said, "Well, I'll address them for you." I'm talking about people who make it known.

I'm very happy with what I've heard today, but I don't have that many people who have been -- how should I say? -- have been made aware of so many of the other things. The common person thinks about what to do to keep them at home, and when they're going to leave the home, they're going to a nursing home without all the other particular types of nursing homes. Then it depends, obviously, on finances. I know, in certain situations, you have to have a lot of money to be in the situation that they are. They've worked all their lives, they sell their assets, they buy the apartment or whatever the case is with it, but they're in luxurious surroundings. Not everybody can afford that.

But this is what I'm talking about. It's got to be more. There has to be more as to what's available as you get old. And we're all aging. I'm still a relatively young man, though.

ASSEMBLYWOMAN MURPHY: Well, I know that because you remind me. (laughter)

ASSEMBLYMAN ROMANO: I'm just trying to be helpful, I'm not trying to be cantankerous. Maybe that's the old age.

We have to develop all these things, that's what I'm saying. There is no one approach. Everybody needs something that's best fitted for them. Community groups, churches, even politicians who are looking to make a point providing some sort of program or whatever the case might be. It's got to get out there. I don't know how many people -- if you ask them, "What do you think of outside the home?" Everybody's going to tell you a nursing home. They're not going to start telling you about all the *A's*, *B's*, *C's*, and *D's*. And I apologize for--

ASSEMBLYWOMAN MURPHY: We need better education, you're absolutely right.

ASSEMBLYMAN ROMANO: That's right.

ASSEMBLYWOMAN MURPHY: That's No. 1 on your priority list.

ASSEMBLYMAN ROMANO: If I'm re-elected, you can be rest assured that that will be. I might ask some of you to give me some good words for my brochures.

ASSEMBLYWOMAN MURPHY: Okay.

Thank you very much.

Kathy, thank you.

Thank you, providers, for being here and for bringing these stories to us. It's part of what we needed to hear. The affordability of assisted living is a real issue for a lot of people, too. And we need to be creative in thinking of ways to address that. And if you have ideas or thoughts or suggestions, please do forward them to us.

ASSEMBLYMAN ROMANO: Let me go back for a moment to the first speaker when I came in.

When we talked about the assisted program, was it in affordable housing units?

MS. CANNON: Subsidized.

ASSEMBLYMAN ROMANO: Subsidized housing. Okay.

ASSEMBLYWOMAN MURPHY: And how does--

Kathy, would you like to come up and tell us a little bit about how that works. When you say the assisted-living program in a subsidized program

-- in a subsidized housing unit, does that mean that those people are living as if they were in an assisted-living unit -- assisted-living facility?

MS. CANNON: They're living in affordable housing or subsidized housing independently. They start to have needs or issues, maybe concerns about medications, have difficulty getting out of bed in the morning, need help with bathing, and things like that. If an assisted-living program provider is licensed in that area, they can then go in to that community. I'll reference the one at Asbury Tower because that's the one I'm most familiar with. That's the building I got licensed when I still worked for Presbyterian Home. So I'll speak to that one.

In that building, as people age in place, the assisted-living program is in the building, and people can come on to the program as they need the services. It's not required of everyone who lives there. They can come on and off as they need the services.

ASSEMBLYWOMAN MURPHY: And they pay per diem for care for that--

MS. CANNON: That's correct.

ASSEMBLYWOMAN MURPHY: --for that care, as if they were receiving it from any human service agency at all. It's simply this is the service that deals with it in that particular facility.

ASSEMBLYMAN ROMANO: I know our next speaker is going to speak about regulations, and I don't know if it's tied in with affordable-- But when they do get the permission or subsidy in their building or such for affordable housing within the architectural plans provided, do they require some sort of a meeting place, No. 1, in the building and for other areas that

would lend themselves through a program should the program be established? Most affordable housing places I see are strictly apartments with a hallway, and the luxury is the space for a car. Now, I don't know what else they have in there when they want to talk to these people or to provide a program like this.

MS. CANNON: They are not being-- When the buildings are being built, it's not with the idea of the assisted-living program coming in.

ASSEMBLYMAN ROMANO: Maybe that's a problem then that we have to address.

MS. CANNON: It's a completely separate process through HUD or HMFA or through other funding sources.

ASSEMBLYWOMAN MURPHY: I think, if I heard Kathy right, what she's saying is that the assisted-living program is the personal assistant helping you out, physically, in your apartment, not trying to put you into a communal sort of thing. So they wouldn't need any of the halls or rooms. They would go into your apartment -- Meals-on-Wheels, or fix your meals.

ASSEMBLYMAN ROMANO: Okay, so maybe I misunderstood.

ASSEMBLYWOMAN MURPHY: It's more caregiving in the sense of homemaking caregiving, not nursing care, but homemaking in your apartment.

MS. CANNON: If you think of it actually as a nice balance between what is home health and what is assisted living -- it's combining those two ways of taking care of people. Home health, traditionally, will go in to somebody's house or apartment for so many hours a day, so many days a week. Assisted living is provided when a person needs those services throughout the

day. So it takes those two pieces together, taking care of somebody in their apartment when they need it.

ASSEMBLYMAN ROMANO: Well, Madam Chair, so what we're actually talking about -- assisted program is the name of programs that provide personal-care attendants, homemakers, a nurse who comes however has been prescribed. And that's what we're talking about then.

ASSEMBLYWOMAN MURPHY: It's not nursing.

MR. ARONSON: It's not only-- An assisted-living program -- and I'm going to speak next, but I guess I can start now.

Assisted-living programs are required to provide social services and activities just like an assisted-living facility would be or comprehensive personal-care home would be. The only difference is that there isn't a requirement for the physical structure of the building.

ASSEMBLYMAN ROMANO: So where do they do this then?

MR. ARONSON: If you don't have the space to do it in the building, then it's your responsibility to find someplace--

ASSEMBLYMAN ROMANO: Okay.

MR. ARONSON: --and to help get the people there. If you do have it in the building, that's great. Then you can do it in your building. But there's no requirement for the physical structure of the building.

ASSEMBLYWOMAN MURPHY: Okay.

June.

JUNE A. DUGGAN: I'm June Duggan, and I'm the President of the New Jersey Association of Nonprofit Homes. We represent many housing providers that do provide assisted-living program services to their members.

And I guess the one thing I want to stress, and I think Kathy's point is well taken, that all these buildings may not have originally been designed to have large communal areas. And there are reasons why they don't. To be affordable, you don't have the luxury of that type of investment. However, these programs, despite that, are very successful besides.

I also think that it's important that when you look at the continuum of services, while this is slightly apart from the discussion that we're having today because you wanted to focus the discussion on assisted living, there is another program in this state that I think is incredibly valuable. It's something called the Congregate Care Program where services are-- And that Program is funded out of casino revenues. And that's a program that brings services into people living in subsidized housing.

Our members have found-- We have many members who participate in this Program. And while it may not be the same types of services that assisted-living provides -- but it provides services that allow somebody to remain independent with dignity in their home for a longer period of time. And it allows them to-- Maybe it means that somebody coordinates Meals-on-Wheels, maybe it means that somebody goes out and helps them do some grocery shopping, a little housekeeping, etc. That has proven to be a really wonderful, cost-effective program that we hope you will also consider when you're talking about the continuum of services that are available to seniors.

We had hoped to have an opportunity yesterday, unfortunately things didn't work out, to talk to Assemblywoman Murphy about that because we have many providers who were -- are providing congregate services. Many would like to provide those services, and the funding has been cut back.

ASSEMBLYMAN ROMANO: Is this the Program that comes under that CCP--

MS. DUGGAN: No.

ASSEMBLYMAN ROMANO: That's separate.

MR. ARONSON: This is State-funded out of the Casino Revenue Program.

MS. DUGGAN: For example, Assemblyman Romano, Whitenberg Gardens -- Mulenberg Gardens and Whitenberg Manor in Jersey City happen to have a Congregate Care Program. I'm sure that Crystal Walden, the manager of those sites, would be happy to talk to you about that if you're interested.

ASSEMBLYMAN ROMANO: But there is a fixed limit. This is not what you might call an entitlement. This is coming out of a fixed budget.

MS. DUGGAN: Right.

ASSEMBLYMAN ROMANO: That's the problem with the CCPED -- I forgot the acronym. But this is-- Everybody says, "I would like to join, or I would like to make use of it," and then you find out there is no money. And then being the young man that I am, I also worry about the young people who cannot afford health insurance.

We had Access -- was that correct, Assemblywoman?

ASSEMBLYWOMAN MURPHY: Yes.

ASSEMBLYMAN ROMANO: --Health Access, and then they sold out two years ago. So you can't even get on the list. They don't even have a list for it. So this is the other part.

But I'm very interested in all of this; although, I don't have to worry because my adopted nieces and nephews said, "There is no way we're going to let you go to a home," so we'll see what happens.

MS. DUGGAN: A home is not a bad place if that's where you need to go, though.

ASSEMBLYWOMAN MURPHY: That's right.

ASSEMBLYMAN ROMANO: They'll take shifts.

ASSEMBLYWOMAN MURPHY: There's some very, very nice ones.

If you have material also, June, that I could duplicate for the members of the Committee, I'd be happy to do that.

MS. DUGGAN: I, unfortunately, didn't bring it with me today, but we'll certainly get some over to you, and certainly we'd be happy to come back with some of our housing providers who are providing congregate services to chat with the Committee or any of the members whether in a form like this or privately.

ASSEMBLYWOMAN MURPHY: Thank you very much, June, I appreciate that.

MS. DUGGAN: Thank you.

ASSEMBLYMAN ROMANO: Would you ask them to contact my office? I forgot my cards today.

MS. DUGGAN: Absolutely.

ASSEMBLYMAN ROMANO: They have the listing.

I'd really like to go and see that.

MS. DUGGAN: Great.

ASSEMBLYWOMAN MURPHY: Andrew--
Kathy, again my thanks. We have amplified--
Thank you, Rick.

Andrew.

Andrew Aronson is the Director of Long-term Care Licensing in Department of Health and Senior Services. And today he is not Susan Reinhard.

Bernice, thank you so much for coming.

ASSEMBLYMAN ROMANO: Oh, Bernice, I'm sorry.

MS. SHEPARD: I got lost, but I drove 85 miles so might as well come in late, and I'm glad I did. (laughter)

ASSEMBLYWOMAN MURPHY: I am glad you did, too.

ASSEMBLYMAN ROMANO: Sit close to me.

MS. SHEPARD: Okay.

ASSEMBLYWOMAN MURPHY: Hi, Andy.

MR. ARONSON: Thank you for the opportunity to address the Council today I guess in a dual role, sitting in for Susan Reinhard and to address you regarding the Department's regulations.

I guess speaking after the other speakers who were so complementary of the Department's regulation of assisted living, I shouldn't say too much about it.

ASSEMBLYWOMAN MURPHY: Well, you better be careful what you say, that's all I can say. You're outnumbered for sure.

MR. ARONSON: By the same token, I'd like to fill in a few things to supplement the discussion we've been having so far.

Kathy began speaking and talked about the continuum of care from independent living to residential health-care facilities, to assisted living, to nursing homes. And I think the first important thing to understand about assisted living is what makes assisted living different from the other places on that continuum. And that's that in assisted living, you can find anybody. You don't need a specific health-care need to be in assisted living.

And that goes to what Joanne was asking before. Somebody who is completely healthy could enter an assisted-living facility and remain in that facility until they die and at all points in between. And that makes assisted living really much different than any of the other types of facilities that were mentioned along that continuum. And that's why, when you think of assisted living, you should really be thinking of it as a concept of a philosophy. Assisted living is something that is provided to people. It's not the setting that it's provided in.

Essential aspects to assisted living -- I'll point out four that we try to maintain through our regulations. Assisted living provides a home-like residential environment in both the public and private spaces to people who live there. Each assisted-living provider has to have the capacity to provide routine services, help on a standby basis and specialized services that need to be available from time to time. Assisted living is a place where people can age in place, and as such, in New Jersey does act as a nursing home substitute in many cases. And finally, the assisted-living provider must maintain a philosophy that emphasizes dignity, privacy, independence, and choice for each resident.

Now, the question is, and the hard part of regulating assisted living is, how do you regulate when part of your goal is to foster independence and to foster choice for each resident, as the speakers before me have spoken about.

The way we do it is to try to make our regulations as nonprescriptive as possible. We try not to have staffing ratios or mandatory discharge criteria or too many other things in the regulations that are required to make all of these places the same and the care for each individual resident look the same. But by the same token, we do have an obligation to maintain some minimum standards of quality in these places. So we really look at quality in five different ways.

The first is competition among facilities; the second is staff training; third is some minimum standards through regulation; fourth is annual surveys; and finally, there are penalties for noncompliance in certain situations. I'll just touch on each of those things very briefly.

Competition is what Assemblyman Romano was speaking about before. It's about notifying consumers about what's out there and trying to give consumers a clear picture of what one place is doing versus another place, versus another place. And it's making that known and allowing new providers who can do better to open up services so that people have that available to them.

The second part of staff training-- We have minimum staff training for people who work in assisted living. We don't have mandatory staff ratios, but we do have minimum training requirements for the administrators in facilities. We do require that an R.N. be available at all times in facilities. The primary caregivers in assisted living are certified nurses or home health

aides who have specialized training in assisted living. And those who go beyond that specialized training to become, what we call, medication aides can serve as people who administer medication to people in assisted living, under the supervision of the R.N., and that's a unique program to New Jersey's assisted-living program.

We do have some minimum standards in our rules that all assisted-living providers have to live by. We have some physical plant standards for assisted-living facilities -- for the purpose buildings that we talked about before. The apartments have to be able to be locked by the resident. Individual toilets, baths, and a kitchenette are required in each unit. Each unit must be prewired for telephone and television reception, and the facility must provide community spaces for dining and recreation.

Now, as I said before, those physical plant requirements don't apply to assisted-living programs, and they don't apply to comprehensive personal-care homes because these are-- The comprehensive care home model was so that providers who already exist could convert to the assisted-living concept and provide assisted living in their buildings without going through some massive construction project that would have been prohibitive.

Each assisted-living provider has to have the capacity for routine services, help that must be available on a standby basis, and specialized services that may be available from time to time.

One of the questions that, Assemblyman, you asked before was what has to be provided in assisted living. No matter what context you're in, whether you're in a facility or a comprehensive personal-care home or an assisted-living program, the provider has to provide assistance with personal-

care, nursing, pharmacy, dining, activities, recreation, and social work. And they have to be able to provide those services to meet the need of each of their residents. It's not a required amount per day, it's resident based. They have to assess each resident and meet the needs of the resident.

There was also the question that came up before about managed risk and about the idea of how much you can let somebody do in your facility and how do we incorporate that. We have, in our rules, a section that deals with managed risk and talks about facilities entering into managed risk agreements with residents of their facilities. So if the facilities identifies a behavior that it considers dangerous to the resident, the facility is supposed to address that with the resident and enter into an agreement with the resident as to how that risk is going to be managed and what is appropriate in that case. The only thing we ask of the facility is that when that behavior starts infringing upon other people in the building, then it has to be addressed. But as long as it is a risk to that individual resident, the facility is supposed to address it with the resident individually.

ASSEMBLYMAN ROMANO: Excuse me, are you talking about whoever said before -- about falling? Are we talking about falling?

MR. ARONSON: It could be falling. It could be the resident who likes to have a drink from time to time. The one story I keep hearing about is the resident who likes to have a drink from time to time, and as long as the resident likes to have the drink from time to time in his or her own room or drinks quietly, that's fine. And the facility is certainly permitted to allow that.

ASSEMBLYMAN ROMANO: It's not liable.

MR. ARONSON: No, once that resident starts drinking in public places and falling over other residents and becoming abusive, then it crosses over a line.

ASSEMBLYMAN ROMANO: What do you call that risk again?

MR. ARONSON: Managed risk.

Another important concept that we like to promote through our rules is that this is a setting where people can age in place. We have a requirement in our regulations that within three years from initial licensure an assisted-living facility or comprehensive personal-care home or an assisted-living program has to have 20 percent of its residents requiring a nursing home level of care. And we do that to try to assure that residents are allowed to age in place rather than being discharged when they have real care needs so that we don't have facilities just taking healthy people in and, then as soon as the care needs increase to a point where they need care, transfer them out. That is not the concept of assisted living in New Jersey.

ASSEMBLYWOMAN MURPHY: What does it say that they must do?

MR. ARONSON: They must have, within in three years of licensure, 20 percent of their residents needing a nursing home level of care.

ASSEMBLYWOMAN MURPHY: What if only 10 percent of your residents do because they're so healthy?

MR. ARONSON: That's possible. What we believe as a Department, when this was created, was that because of the age of the resident who is going into assisted living-- The average age of somebody going into assisted living is about 82 years old right now in this state.

ASSEMBLYWOMAN MURPHY: Oh, my.

MR. ARONSON: And based upon that, the idea-- Many people who are in the facility for a period of three years -- their care needs will increase as they are there.

MS. EDELSTEIN: Excuse me, how is nursing home level defined, by whom, with what criteria?

MR. ARONSON: In our rules it's not very clearly defined. Nursing home level of care is defined on the Medicaid side as 2.5 hours of nursing care per day. We have not created a new definition of that, nor do we intend to differentiate between 19 percent or 20 percent or 21 percent. It's a concept. We're trying to promote the concept more than the strict rule.

MS. EDELSTEIN: So being held to the 20 percent isn't going to be the issue. It's more that you're adhering to the philosophy.

MR. ARONSON: Correct.

ASSEMBLYMAN ROMANO: Excuse me, Mr. Aronson, do you go out in the field?

MR. ARONSON: No, sir.

ASSEMBLYMAN ROMANO: Oh, you don't, you don't go out.

MR. ARONSON: No, I'm not a surveyor. We have a staff of surveyors who go out into assisted-living facilities. We have annual surveys, and the surveyors go out and look at outcomes as much as anything else to try to make sure that people's care plans are being followed and that their assessments are appropriate and that activities are being provided and social work is being provided. And those people are specifically trained nurses.

ASSEMBLYMAN ROMANO: No, I was going to ask you if you had ever visited the Fritz Reuter Altenheim in North Bergen. They've developed a program you might call continuum. At one time, it was just a nursing home, but now they've added on -- they have condominiums.

You've been there?

MS. DUGGAN: They're a continuum care retirement community.

ASSEMBLYMAN ROMANO: How's that? Did I hit it right on the head?

MS. DUGGAN: You got it.

ASSEMBLYMAN ROMANO: I think it's excellent. I think they have an excellent program.

MS. ROBINSON: Andy, I'm back to the 20 percent who require nursing home care. Is it then the responsibility of the assisted-living program or facility to continue to care for those clients and provide the level of care that they need -- bring in -- up the services or--

MR. ARONSON: We have, in our rules, eight discharge criteria which are suggested. They're not mandatory. A facility can use discharge criteria as it agrees with the resident. So each person who goes into assisted living would sign an agreement with the facility that would set forth the discharge criteria. What we would expect is that the facility would be able to provide the services that are necessary and not be discharging people before they need those services.

Finally, I just want to touch a bit, because it's come up so much in the Medicaid payment for assisted living-- I'm not an expert on Medicaid payment, but just to clear up some of the things that were said before. The

amounts that were said before, \$60 per day and \$50 and \$40, are per diem rates, and that's for the care. An assisted-living facility, for example -- the reimbursement is \$60 per day. It would be \$1800 per month. In addition to that, the resident pays a room and board fee. If they're an SSI resident, the room and board is, I think, about \$530. I believe that's the amount. So the total reimbursement to the assisted-living providers between \$2300 and \$2400 per month in an assisted-living facility.

Right now, we have, I believe, out of the comprehensive personal-care homes that exist in the state, approximately 77 percent of them accept Medicaid as payment.

ASSEMBLYWOMAN MURPHY: Twenty-seven percent?

MR. ARONSON: No, 77 percent. Out of the assisted-living facilities that exist in the state, it's much lower. It's around 25 percent.

ASSEMBLYWOMAN MURPHY: Okay.

MR. ARONSON: If you have any questions, I will be happy to answer them.

ASSEMBLYWOMAN MURPHY: Yes, Bernice.

MS. SHEPARD: Are there any assisted-living places in New Jersey that are low income? And I don't mean very poor. I mean people who are just barely making it -- can go into? Are there any in New Jersey?

MR. ARONSON: Most of the assisted-living facilities -- the buildings that were built for assisted living are not serving low-income populations. There are some that are accepting Medicaid reimbursement, and that would be available for a low-income person.

The comprehensive personal-care homes that we see are accepting lower income-- It's still not cheap. I wouldn't say that. And the assisted-living programs are also accepting lower income as compared to the assisted-living facilities. But what we've seen, as far as Medicaid goes, is that that population is mainly in the comprehensive personal-care and the assisted-living program.

ASSEMBLYWOMAN MURPHY: And the assisted-living program again is one that would be served in a subsidized housing facility.

MR. ARONSON: Correct.

ASSEMBLYWOMAN MURPHY: And it's programmatic, not a physical change of the building itself.

MR. ARONSON: That's right. The nice thing about that, for a lower-income person who is living, is that they wouldn't have to move out of the building. They can get the care and services right where they've lived.

ASSEMBLYWOMAN MURPHY: But it is a lack. You're correct, Bernice, it is a lack. There aren't facilities being built for that population, and we're aware of that.

MR. ARONSON: That's what we're seeing. Thus far, we haven't had purpose built facilities that are designed to serve that population.

MS. ROBINSON: I've seen some assisted-living facilities that are specialized. There's one in Cherry Hill dedicated to serving residents with Alzheimer's disease. I'm wondering if there's special surveillance or special requirements as far as-- I'm a nurse, so I think about vigilance and the needs of people who are cognitively impaired, too.

MR. ARONSON: It's good that I was at the meeting that Kathy referred to this morning because we had a long discussion of this.

We require, in our rules, that the facility meet the needs of its residents. So when the resident comes in, the resident must be assessed and a care plan has to be developed, and the person's needs have to be met. So if that person is cognitively impaired and needs some additional assistance, the facility should be providing the assistance. We don't make it mandatory. We don't say, "On an Alzheimer disease unit, you have to increase staffing." There's no rule like that. It's based upon the individual resident assessments.

MS. ROBINSON: Okay.

ASSEMBLYWOMAN MURPHY: And because these are private facilities, they can turn down someone as being someone whom they cannot adequately serve within the framework of any program that they may be able to access.

MR. ARONSON: Yes, that's correct.

ASSEMBLYWOMAN MURPHY: And would an assisted-living program be able to do the same within a subsidized housing unit if there were someone whom you felt your services could not serve to the extent that is within your contract?

MR. ARONSON: Sure.

ASSEMBLYWOMAN MURPHY: Well, sometimes it's hard to say no to these things and still continue. There are often some deterrents.

MR. ARONSON: Yes, if there was somebody in an assisted-living program who the assisted-living provider could not serve -- could not meet their needs-- Yes, it would be appropriate to tell that person, "We can't meet your needs here."

ASSEMBLYWOMAN MURPHY: Okay.

Are there further questions, ladies and gentlemen? (no response)

All right, Andrew, thank you. Won't you put your other hat on and come on back?

We wanted to talk to someone about the Alzheimer's Association's recommendations for the Council regarding training needs.

Sue Lachenmayr was to have come at another time, but her time had been eaten up and chewed up, so we said, "Come on down." So she was kind enough to move her schedule around and do so with us.

Thank you, Sue.

SUE LACHENMAYR: Don't get scared, I'm not going to go through all of it. (referring to testimony)

ASSEMBLYMAN ROMANO: Is there another copy of this for Bernice? (referring to witness's testimony)

ASSEMBLYWOMAN MURPHY: Yes, there is one here for her.

MS. SHEPARD: You've been talking about assisted living, and I've gone through some experiences. A girlfriend of mine moved from Lawrenceville. She went into an assisted-living place. It cost her \$168,000 with some (indiscernible) provisions if she doesn't take her meals and all that stuff.

In any event, she's four years older than me, and neither one of us have sense enough to know we're old. And when she moved to the assisted living, I said, "You just think some of those old men will fall in love with you and be crazy enough to marry you." Well, I called her one day and she said, "I'm in love. But you know what it's like because you've been there."

“I fell in love with the wrong man. He’s a retired policeman, a republican conservative,” and she’s as liberal as they can get. But she said, “I love it.” And she moved in with him on February 1, and I haven’t heard from her since. I guess they’re close. (laughter)

ASSEMBLYWOMAN MURPHY: Bernice, we’re all going to be asking every time, “Have you heard from your friend?” (laughter)

MS. SHEPARD: I thought that you might like that because you old guys play cupid whether you know it or not.

MS. LACHENMAYR: Well, that is a hard act to follow.

Madam Chair and members of the Council: I just have to thank you for the very important work that you’re doing. And I really do appreciate the opportunity to speak before you.

Unfortunately, I’m not an expert, as so many of your speakers today, but I do come to you with a great deal of information. And as you know, I’m representing the Alzheimer’s Association here in New Jersey.

What I’ve given you is really an overview. And we’ll talk about some of the different pieces of it. And I have some recommendations as the final piece.

What I really wanted to sort of describe to you today is the difference between dementia care and some of the care that we’ve heard about today and I’m sure you’ve heard about in previous testimony. And basically when I’m speaking about a caregiver today, I’m really talking about anyone who might come in contact with an individual who has dementia. So it might very well be a nurse or a health aide or a certified nursing aide or a paraprofessional. It could be a volunteer, or it could be a family caregiver.

And I'm really-- When I talk about dementia training, I'm really talking about training that could easily go to any of those groups.

In New Jersey, our regulations right now do not require dementia-specific training for any of our levels of care, regardless. Certainly, there are facilities who do train personnel and staff on their own, but there's nothing that we've mandated so far as dementia is concerned. We have-- I think they were already addressed by Andy. The minimum standards for certified nursing aides do include training in basic nursing skills. They have an internship, and then they do have annual ongoing training about care-specific issues. It could be dementia or something else, but as I said, nothing is really mandated.

I want to take you back just a little bit. As I began to do research in order to do this testimony, I found that in September of 1983, Governor Kean signed legislation for an Alzheimer's Disease Study Commission. The recommendations in 1983 were, one, to develop guidelines for care of Alzheimer's patients in nursing homes; to provide expanded adult day care programs; and to address the need of agency staff to become more knowledgeable and sensitive to the special needs and management of people with dementia. Our Department of Health, in collaboration with experts, in fact, put this manual together in 1983. So we have something on the books.

The truth is, there certainly does need to be revision of this because there are a lot of different philosophies now in care. But I just want you to know that in 1983, we began this work and really-- As you know, the problems are still here, not that they're going to go away today with the effort of this Council in an afternoon, but hopefully over time some of them can be

addressed. We really still are dealing with the challenges of people who have dementia.

And I wanted-- We talked about levels of care, and just a little brief definition-- Skilled care is really trained personnel who are providing medical expertise. And they're really doing that to help an individual to recover from something. This is care that's given in the expectation of recovery from an acute illness, a broken hip, surgery, or something like that.

Custodial care, which is, I believe to a great extent, what has been described in the assisted-living information that we've seen today, is really primarily delivered by trained paraprofessionals, again certified nursing aides. They know how to lift someone, turn someone, how to provide help with dressing, eating, bathing, and those kinds of things. Both of these levels assume that the individual that you are working with has the cognitive ability to interact in some way with you.

When we speak about dementia-specific training, we're really talking about an entirely different approach. It's not skill based, it is really more philosophy based. And it is the ability of someone to be able to interact and communicate in a proactive fashion with people who have cognitive impairment. So it really is something that needs to be addressed over and above existing training for professionals.

I wanted to give you some examples of some stories about sort of what it's like to deal with somebody who has dementia. And these are stories from our program coordinator who used to work in a nursing home facility. She said that she had one woman who paced constantly from sunrise to sunset. They could not contain her in any way. That meant that when they fed her,

they had to put the food in small little bits and walk with her in order to get the food into her. It meant that there was no opportunity for any other kind of activity. Now, in many facilities, this woman would have either been medicated or restrained because her pacing was so extreme. In this instance, the staff really did have some training, and what they did was to learn to walk with her and to begin attempts to communicate with her -- to do some music therapy and some other things responding to her needs.

In a second scenario, Piper told me that to do an activity, whether it's in a nursing home or an adult day care, imagine that you have 20 individuals with dementia who are pacing, yelling, screaming, performing repetitive behaviors. They're all over the place, so it's an unbelievable challenge. And the staff truly does need to have a certain amount of training in order to deal with that.

She talked about one gentleman who would spit repeatedly on the floor, and then, of course, other people would get upset. Well, this is a behavior that, in some way, might be restrained in some facilities. In this instance, they discovered that if they gave that gentleman a cup with liquid and a straw, he wouldn't spit. So it meant that somebody had to keep filling up his glass, but it also meant that they weren't having to restrain him or medicate him in some way.

Another instance that she told me about was a man who would constantly expose himself and then would begin to use very inappropriate language as he was doing so in front of staff, in front of other residents. Here, truly, would have been a case where this individual would have been removed from the floor and certainly restrained. And when they did some exploration,

they realized that the man's wife, in an effort to be helpful, had changed his clothes to sweatpants. And without that cue -- we've talked earlier about that cue -- of zipping up the pants and buttoning them, this man was completely obsessed with something very unfamiliar.

So in a situation where professionals and paraprofessionals don't have the training about dementia, they can make some very different diagnoses and some very different ways of treating people.

I have, just briefly, a little notation from a paraprofessional in Illinois who has gone through special dementia training. And she said, "This course has opened my eyes in many aspects. I never realized how difficult it could be to know that you're losing your memory slowly every day, to be around your family and see them as strangers or as someone who wants to hurt you. So much fear occurs. It's hard for a resident to feel safe. There are so many little things a caregiver can do: give encouragement; speak slowly; during mealtimes, use smaller plates and finger foods; make the resident part of the conversation. Caregivers and staff almost need to be actors and actresses when they're dealing with dementia." So it truly is a very different concept.

Among the things in your packet that I've given you, in the second-- Well, the second part is our regulations and also an analysis by the Alzheimer's Association of sort of where the training that's mandated here in the state is and also assisted-living regulations and what we have. And in many cases, New Jersey stacks up similar to the rest of the country.

In the second part, I have given you an article on the staffing crisis in nursing homes and also some more descriptions about assisted living and quality care for dementia throughout the nation. So that may be helpful as

you're looking at different issues. But in particular, I wanted to just point some things out about the certified nursing aides or the home health aides that do-- What we know is that about 80 percent to 90 percent of care of individuals who are elderly and specifically of those who have dementia-- There's a tremendous shortage in this occupation. The result is that the staff receives little training, they're inadequately supervised, and they're required to care for more residents than they can properly serve.

Right now, nursing home populations have people who are sicker and more frail and certainly have more cognitive disabilities. And this has resulted in increased injury rates among paraprofessionals. In 1995, the injury rate was higher for aides than for people in coal mining or in construction.

Aides, as part of their responsibility, are frequently feeding someone, and about 50 percent of them are never able to complete feeding patients. The patients start to slow down, and it's impossible, under the current staffing conditions, for staff to have enough time. The result is really malnutrition, weight loss, and death. So that whole concept of our paraprofessionals is an entirely greater problem than even just the dementia care.

So then I have the next section for your late-night reading is what some other states have done and are doing, specifically advisory councils on Alzheimer's disease. States who have mandated training-- California is looking at a bill that they are certain is going to pass this year that mandates two hours of dementia training. Oregon has much more extensive legislation, and they are mandating dementia training at a much higher level. So there are models of these things in that next packet for you to look at.

In addition, I think it's really important to understand that even as people are careful in assessing assisted-living and identifying cognitive limitations-- We know that certainly, as people age in place in assisted living, if they're in adult day care, or if they're in nursing homes -- we now know that about 75 percent of that population has dementia. So we're talking about a huge population that really does need to be addressed.

I think the-- I have a little more detail about some of the other people's training, but I think that it's in this packet, and I'm very comfortable with your reading it and referring to it. And I can answer any questions about that.

The next section that I have for you are some model programs on dementia training, and they're really some new and different concepts. The Rush staff training, that's the first one in here, really builds -- it's primarily done with paraprofessionals. We're talking now -- the certified nursing aides or home health aides. It's done with a model that really rewards and supports and reinforces that group of people, so they have a sense of empowerment. And it really encourages them to feel that they and their work are special and extraordinary.

There is also information about an activity-based care program which really talks about the concept that rather than chores to get done, every interaction with a person with dementia is an opportunity to interact and to consider that as an activity. We tend, in our minds, to think of an activity as something that is recreational and fun as opposed to something we have to do. So when we now talk about activity-based care, we're kind of switching that

concept to being something that's much more positive rather than something that's restrictive or repetitious.

In addition, in your packet, there is the outline for-- Our northern New Jersey Chapter does an extensive training program with volunteers where they take healthy seniors and take them into the home to do art and recreational therapy with people with dementia. So I've included that.

And finally, I have only the assessment tool for a program that's called Best Friends. That was written by two people with the Alzheimer's National Association. The concept here is not too different from these other things. And the concept is one of care in terms of people being friends rather than someone delivering care to someone else. So it does really change the relationship and that part of-- The philosophy is that part of the responsibility of the caregiver is to really interact and to become the memory of that person who's losing theirs. So it's really emphasizing on a different way of managing dementia. And then I do have other models. Obviously, we're in the business of training at Alzheimer's, so I have a caregiver manual and I have key elements of dementia care which I'm happy to leave with you.

I also want you to know that there are a number of facilities that have some really remarkable training tools that they've developed on their own, and I'll also leave this. This is Manor Health Care -- their training manual for the individual who is doing the training and a workbook that they utilize in their facilities for their staff. So it isn't that there aren't training models out there. There absolutely are. And I think it would be extremely helpful if we could define some terms and come to what our expectations are in this state in overview.

The next section that I have for you is really just key concepts in dementia training, and it's a bill of rights, which sounds very similar to the assisted-living philosophy, which is that people are individuals and they do have basic rights. They need to be treated as adults. And, certainly, one of the key concepts is trying to start with people from what their assets are rather than what their deficits are. When we talk about activities of daily living, we tend to rank people in what they can't do as opposed to starting where they can start.

And then really some goals of care and the role of caregiver and ideas about ongoing training, and what the National Association does recommend as a staffing ratio in dementia care units, which is six-to-one-- So that, obviously, is a different model than something you might do in assisted living, but that's the National recommendation.

And then, finally, I do have a number of recommendations that I would like the Council to consider.

And the last really being the hope -- the sincere hope that the Council recommends that they be ongoing-- I think that, although you are an advisory council -- and the hope was that you would come up with answers. I know that you've got as many future challenges as probably do answers.

ASSEMBLYWOMAN MURPHY: More questions than answers by the time we're--

MS. LACHENMAYR: That's right. So I'm really hoping that you would consider mandating a permanent status for the Elder Care Council and, in specific, have a component that will look at dementia to identify and minimize the gaps in services for people with dementia and their families,

realizing that cognitive impairment is of equal importance to physical impairment. And, secondly, designing -- helping to design appropriate flexible financing for services. And, thirdly, identifying and recommending training standards for dementia care in residential, in community, and in home settings.

And the Alzheimer's Association would be thrilled and pleased to work with the Council and certainly continue to work with the Department of Health to work on these kinds of suggestions.

ASSEMBLYWOMAN MURPHY: Susan, the task force that you mentioned that prepared the book in front of you--

MS. LACHENMAYR: Yes.

ASSEMBLYWOMAN MURPHY: Is that task force still meeting? Was that task force dissolved?

MS. LACHENMAYR: No, I don't know that it has met.

ASSEMBLYWOMAN MURPHY: Is it dissolved, ongoing, is it still on the books, or is it gone?

MS. LACHENMAYR: It was-- When the Council came forward with their recommendations I think it was--

ASSEMBLYWOMAN MURPHY: They turned in their recommendations and that was the end of it.

R I C K G R E E N E: The final report was submitted to then Governor Kean back in 1986, I believe.

ASSEMBLYWOMAN MURPHY: Well, sometimes they turn in the reports, and then they still exist only there's no one there.

MS. LACHENMAYR: That's what I'm hoping for you.

ASSEMBLYMAN ROMANO: Madam Chair, if you will allow me a few questions--

ASSEMBLYWOMAN MURPHY: Yes.

ASSEMBLYMAN ROMANO: I don't know your level of medical expertise, and I'm not looking for a scientific study-- Is there any hope, let's say, of improvement of people who are involved with Alzheimer's? That's number one. Number two, what do you do with someone who is at, I might say, the complete edge where they don't recognize loved ones? It's like talking almost to a stranger. Now what we're talking about is no longer adult day care. Now we're talking about full confinement in a nursing home.

MS. LACHENMAYR: Well, actually, people can age in place in an assisted-living facility and at home. It is extremely intensive care. I don't want to mislead anyone. The end stage of Alzheimer's -- individuals can no longer swallow, and they are nearly comatose in that end stage. So it's really a tremendous challenge. And the families who do keep someone at home--

ASSEMBLYMAN ROMANO: Is there any hope for improvement?

MS. LACHENMAYR: Well, actually, we're doing some exciting things, and I'm glad you asked that. We, first of all, now are coming very close to-- We can now diagnose much more completely than we could. Before it was sort of a diagnosis of, "We throw everything else out. It's not this, it's not that." Now we can identify and diagnose Alzheimer's. It used to be that we could only really do that by doing a brain biopsy or an autopsy. We are beginning to look very seriously-- We have only two medications right now that are used. One is Cognex and the other is Aricept (phonetic spelling).

There are about three more that may come on the market by the end of the year through the FDA. They are all for early stage -- somebody in the early stage. So it's going to delay and lessen symptoms.

ASSEMBLYMAN ROMANO: Yeah, but what does the medication do?

MS. LACHENMAYR: It delays and lessens the symptoms.

ASSEMBLYMAN ROMANO: Okay.

MS. LACHENMAYR: And some people have claimed actually some improved cognitive ability. Again it's only going to be effective for a certain amount of time, and then that decline will happen.

What we are spending a lot of the research dollars on is really looking at prevention and delay of onset. We know now that 20 years before a person actually has the symptoms of Alzheimer's they can be diagnosed as having the potential.

So think about that in this room. Twenty years before symptom one shows up, if we can start now doing things-- And there are things that-- The interesting thing about prevention is that most of the prevention-oriented suggestions are affordable: estrogen therapy, anti-inflammatories, antioxidants, Vitamin E and Vitamin C. They're doing a huge national study right now to really determine what is effective. So if we can delay onset of symptoms and delay onset of the disease, then we're going to be in much better shape. So I would say -- I'm hoping to say that within the next 10 years, I think you're going to see some real differences in how we can treat and manage. But it is a disease of aging, so I don't believe that is going to go away. If we can keep

people -- that they don't get the disease until they're 90 or 95 years old instead of starting when they're 65 years old--

ASSEMBLYWOMAN MURPHY: I will repeat something, Sue, that is in mind I guess having worked on some different subjects in the task force. We've got to get it out of this world. And as we keep eliminating some of the easy ways, nature only brings us the tough ones to deal with.

MS. LACHENMAYR: And you're right, Alzheimer's is one of the toughest.

ASSEMBLYWOMAN MURPHY: It is a really tough thing for everybody so--

ASSEMBLYMAN ROMANO: That brings up a point though. In adult -- I'm sorry, day care, I don't think we've ever had -- nobody's put together for us the right day care for senior citizens. Now, from what you're saying, I see already that adult day care should encompass some sort of mind-training type of situations so that it is just like a mental aerobic. How do you like that one?

MS. LACHENMAYR: Yes, the Adult Day Care Association does encourage that, and the majority of them do. And I can certainly give you names if you would like to speak to people from that organization.

ASSEMBLYWOMAN MURPHY: There are Alzheimer day care programs now, which are very definitely directed to stimulus of that function.

ASSEMBLYMAN ROMANO: But you and I are committed to--

ASSEMBLYWOMAN MURPHY: I've been giving my money for a while. I'm buying my slot.

ASSEMBLYMAN ROMANO: We're trying to protect it, making sure that that money is replaced that was cut in budget.

ASSEMBLYWOMAN MURPHY: Yes.

ASSEMBLYMAN ROMANO: We will do that, Assemblywoman.

MS. ROBINSON: Madam Chair, I need to leave, and I apologize. But before I go, I just need to say that as someone who has been in long-term care and nursing education since 1983, we need to do this.

ASSEMBLYWOMAN MURPHY: Yes.

MS. ROBINSON: Dementia care education is just so lacking. And some kind of requirement or strong encouragement that all caregivers avail them of this is just long overdue.

ASSEMBLYWOMAN MURPHY: At the last meeting of the Committee, I asked the members of the Committee to put down their 10 priorities in terms of the report that we will be preparing for the Governor, and Joanne has done that. You need to know that high on her list is the education to which you speak today and further education for all caregivers.

Thank you very much, Joanne.

Ladies and gentlemen, unless there is further business to come before this group, we will adjourn the meeting, and we will have a tour of Morris Hall for those who would care to accompany us.

(MEETING CONCLUDED)