
Public Hearing

before

NEW JERSEY ADVISORY COUNCIL ON ELDER CARE

“Testimony concerning health care and caregiving for the elderly”

LOCATION: Senior Citizens' Center
Neptune, New Jersey

DATE: December 12, 1998
10:00 a.m.

MEMBERS OF COUNCIL PRESENT:

Assemblywoman Carol J. Murphy, Chair
Assemblyman Samuel D. Thompson
Assemblyman Louis A. Romano
Len Fishman
Susan C. Reinhard
Ruth M. Reader
Theresa L. Edelstein
John Michael Heath
Roberto Muniz
Joanne P. Robinson



ALSO PRESENT:

Irene M. McCarthy
Office of Legislative Services
Council Aide

Hearing 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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ASSEMBLYWOMAN CAROL J. MURPHY (Chair): I'd like to ask you please to allow us to proceed with our meeting. We have a welcoming committee, and they will be welcoming us here this morning, I understand.

R O S E M A R Y G R A Y: Good morning and welcome to Neptune Township. I'm Rosemary Gray. I'm the Director of the Senior Center here, and it's a pleasure, on behalf of our Township Committee, to welcome you to Neptune and to wish you a very happy holiday. And I'm hopeful and optimistic that the issues that will be brought to light today will be -- will help pave the way for our seniors and our caregivers in the future.

So we're really looking forward to this, and it's an honor to have you and assisting the panel. And without further ado, I'd like to introduce Alma Strack, the Acting Director of the Monmouth County Office on Aging.

Thank you.

A L M A S T R A C K: Thank you, Rosemary.

On behalf of the Board of Chosen Freeholders in Monmouth County, I would also like to welcome you here today and to thank Rosemary for the use of this beautiful Senior Center. It's obvious the amount of work and the amount of service that goes to seniors from this center every day.

I'd now like to introduce Carol Murphy -- Assemblywoman Carol Murphy, the Chair of this Commission.

Thank you very much.

ASSEMBLYWOMAN MURPHY: Thank you very much, and thanks to both of you and to your Board of Freeholders. This is a very

gracious gift, the ability to be here; thank you so much and for the wonderful goodies you put out for us. Appetites never fail, I can see. Thank you.

Ladies and gentlemen: I'm going to ask the members of this Council to introduce themselves to you, indicating what their relationship is here on the Council, what their relationship and interest is so that you will have heard their voices and personally had a sense of them. After that, I will go through the agenda very quickly with you, and we will begin the meeting.

Assemblyman Louis Romano.

ASSEMBLYMAN ROMANO: You said it best. I'm Assemblyman Lou Romano, from Hudson County. Remember Hudson County? That's where you all came here from. (laughter) And I happen to be a senior citizen.

DR. ROBINSON: I'm Joanne Robinson, and I'm an assistant professor of nursing at Rutgers University. I'm here representing the New Jersey State Nurses Association.

MS. EDELSTEIN: Good morning. I'm Theresa Edelstein. I'm the Director of Continuing Care at the New Jersey Hospital Association.

MR. MUNIZ: Good morning. I'm Roberto Muniz. I'm from Bergen County, north of Hudson. (laughter) I'm the President for Francis Parker Nursing Homes in Piscataway and in New Brunswick. And I'm here representing the Commission on Aging.

DEPUTY COMMISSIONER REINHARD: I'm Susan Reinhard. I'm the Deputy Commissioner of Senior Services in the New Jersey Department of Health and Senior Services.

ASSEMBLYWOMAN MURPHY: Would you like to wait a bit and then say a little something?

COMMISSIONER FISHMAN: Sure, okay. Sure.

ASSEMBLYWOMAN MURPHY: We're going to hear from the Commissioner a little more in full, if you please.

Assemblyman.

ASSEMBLYMAN THOMPSON: Assemblyman Sam Thompson, 13th District, which is parts of Monmouth and Middlesex County, member of the Assembly Health Committee.

ASSEMBLYWOMAN MURPHY: Thank you.

DR. HEATH: Good morning. John Heath. I'm a physician doing geriatric medicine. I help direct a training program for physicians within The University of Medicine and Dentistry of New Jersey in geriatric medicine.

MS. GREENBERG: Good morning. I'm Vivian Greenberg. I'm a clinical social worker in Pennington, New Jersey. My area of specialty is caregiving. I write books, and I lecture throughout the country on the considerable stresses of giving care to elderly parents, which I'm sure you all know about, and I look forward to hearing your testimony today.

ASSISTANT COMMISSIONER READER: Good morning, Ruth Reader, Assistant Commissioner, Department of Health and Senior Services, Division of Senior Affairs.

ASSEMBLYWOMAN MURPHY: And now, Commissioner Fishman.

COMMISSIONER FISHMAN: Thank you.

Well, good morning, everybody. Wonderful that you were able to come out. And I want to thank you, Chair, Assemblywoman Murphy, for having the idea that we need to have some public hearings on Saturdays, when

people who otherwise might not be able to attend a hearing during the week would be able to come and give us their thoughts.

I want to join her in thanking the folks at this Center here in Neptune and the folks in Monmouth County for making this day possible.

This is an effort by the Governor, together with members of the Legislature, to learn about the needs of folks who are providing care to senior citizens, and for seniors to speak about what they need, the kind of assistance that we in State government can provide. The hearings that we've had so far have been very instructive. Hearing from folks who are actually living with these issues is really more illuminating than reading volumes of statistics and information. So this is a very important effort. I can promise you that the Chair and I and members of this Council will take your words back to the Governor and the Legislature so that we can do more effective planning on your behalf in the future.

So again I thank you all for coming out, and I thank you, our Chairwoman, for deciding to use this site and this day to hear from people in this community.

ASSEMBLYWOMAN MURPHY: Thank you.

And just because we are not, any of us, geographic specialists, I do believe Neptune is still in Ocean County, am I correct? (negative response from audience)

No, it is in Monmouth? (affirmative response) I got advice from my left. That's why you should always listen to the folks on the right. (laughter)

On the agenda of the speakers this morning that you have in front of you, there are a couple of changes. If you would look down the list, on the first page, following John Barrett will be Caroline Murphy. She has requested that she be moved forward. She had signed up previously. So if you would insert the name, after John Barrett, of Caroline Murphy.

Please remove Janet Manet, from Monmouth Medical Center. And further down, below Mr. Applegate, there is a name, Ken, and the proper spelling of the name is Z-A-E-N-T-Z. That change is also to be made on your list.

Cecily Quinet is not here. She was on the second page, from the Monmouth Geriatric Program. Cheryl Ferwick will not be testifying this morning, either. And at the very bottom, if you will put in Keith Lannon, as a caregiver, that's L-A-N-N-O-N, and Carol Mazic as a caregiver.

We, I think, have come to the corrections that needed to be made.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Do you have any more agendas?

ASSEMBLYWOMAN MURPHY: These are just the names of the people who will be testifying. They will introduce themselves, and it has been given as a guide for all of us so that we could make notes of things that we think are pertinent as they speak to us. I'm sorry that there are not that many, but that is not an agenda, as such. The agenda is just hearing people and making notes on this.

We have a number of people who will be testifying this morning and into the afternoon, so we will be asking people to limit their remarks to a

five-minute period. We will take any written testimony. Make sure that it is recorded and distributed among the members of the Council.

Our purpose here today is to listen to you, because if we are going to plan, in this state, to accommodate the needs of an incredibly increasing number of senior citizens and those of us who are hitting milestones that our families, our parents, and our grandparents never even thought would be achieved in the normal course of events, we need to plan how we will be living, as we become less able but still very clear about our living conditions.

We need to make some decisions. We need to plan ahead. We need to make sure the generation following us does their planning and their homework. We need to help them understand what we expect, what we need for assistance, and how we are going to provide for that, both economically and physically.

So we're here today to hear you. We thank you very much. And if I give you a little sign that says your five minutes is over, please understand it's not because we're not interested. It's because there are so many of you who have a clear need to be very clear to us, and we want to hear you all. But we do know that the 25th of December and Hanukkah, all these wonderful events, will come on time, and we need to be home for them. (laughter) Thank you.

The first speaker this morning is John Hanifin. Is John Hanifin here?

JOHN HANIFIN: Yes, ma'am.

ASSEMBLYWOMAN MURPHY: John, would you like to come up to this microphone and testify for us.

John is a client, I believe.

Multiple sclerosis, John?

MR. HANIFIN: Right.

ASSEMBLYWOMAN MURPHY: Joan Powers, of the VNA, is your transporter, and Joan is sitting at that other table.

MR. HANIFIN: Is this on? (referring to PA microphone)

ASSEMBLYWOMAN MURPHY: Yes, it is, John, thank you.

MR. HANIFIN: I'm glad you mentioned the disease part, because I didn't want everyone to think I was a senior citizen. This white hair, I don't know how it got here. (laughter)

ASSEMBLYWOMAN MURPHY: You woke up one morning and it was there.

MR. HANIFIN: It was there.

Assemblywoman, Commissioner, Assemblypeople: I have multiple sclerosis. You're saying, "Why don't people prepare themselves for these things?" Well, you don't prepare yourself for a disease. And, no, I did not want to retire when I was in my early 40s, but being disabled makes you do these things.

I am very grateful for the programs that are available to me. The drug program from the State and the CCPED, it allows a home health aide to come into my home to keep my home -- I live alone -- to keep my home clean, to keep my clothes clean, and to keep me clean, and to make sure that there are certain things in my refrigerator that she thinks should be in there.

And without her, I think I would probably be in a nursing home, and I think I'm a little too young for that. And it's a great thing to be able to

have, and I think society looks at itself and society is judged on the way they take care of their elderly and the disabled.

And we know our ancient history of Sparta, and even in this century we're in, there was a certain regime in Germany that didn't treat their elderly and disabled too well. And I think we ought to realize there are many people who are elderly and disabled out there who don't -- who are not reached by the people who offer these programs.

And a society is something like a piece of fruit. If it has a mark on the outside, you can cut it out and it will be good. But when it starts to rot from the inside, the fruit is no good, and it just rots away.

So I think we should look at it and listen to society. And there are numerous dollars spent in this state and throughout the country, for that matter -- throughout the county -- which someone who needs these programs that are not getting, if they were to pick up a newspaper and read where the money is going, would be shocked.

And I would just like to offer my appreciation to the program and to all who make it possible for me to live in my home the way I want to live, without being in a nursing home.

Thank you very much.

ASSEMBLYWOMAN MURPHY: Thank you very much for being here this day. We really appreciate it.

MR. HANIFIN: I expected Henry Hyde, when you said five minutes. (laughter)

ASSEMBLYWOMAN MURPHY: Well, I'm sure we seem just as abrupt, but it isn't that.

MR. HANIFIN: We don't want to go there.

COMMISSIONER FISHMAN: Thank you.

ASSEMBLYWOMAN MURPHY: And thank you, Joan, for helping John to get here this morning and to be with us. Thank you.

MR. HANIFIN: Thank you.

ASSEMBLYWOMAN MURPHY: The next speaker will be Sharon Anderson, who is a caregiver.

Sharon Anderson. (no response) Okay.

Eileen Taylor, who is a client of Sharon Anderson. (no response)

So neither of them are here. All right.

Patricia Buckley, Program Coordinator for Alternate Family Care, Department of Health and Senior Services.

PATRICIA BUCKLEY: Good morning.

COMMISSIONER FISHMAN: Good morning.

ASSEMBLYWOMAN MURPHY: Good morning.

MS. BUCKLEY: I am Pat Buckley, from the VNA of Central Jersey, formerly NCOSF. And the VNA of Central Jersey has more than an 85-year history of providing community-based and visiting nurse services in Central Jersey.

Since its inception, we have been involved in the CCPED Program, and we have advocated for services to senior citizens and for the expansion of this Program, since the beginning.

I don't think that I have ever served on a committee -- and I serve on a lot of committees -- where I have not heard consumers voice their wish to age in place. And when they say age in place, they do not mean to move

somewhere else to age. Seniors have overwhelmingly voted, in every capacity, to have the availability of services in their own home. Now, sometimes they do have to sell a home and move to a senior citizen building, but they want to stay in that setting. They want their friends and family nearby, and they do not want to be moved.

I had the opportunity, about five years ago, to serve on a long-term care committee, where for months we deliberated -- it was providers and consumers -- about how long-term care slots should be allocated throughout the state. And although some of the slots were to go to nursing home beds, because that is necessary in some instances, most of the votes went to CCPED. And yet nothing happened, and almost all the slots went to nursing home beds.

Therefore, I have been and I continue to be a proponent and an advocate for CCPED. And I'm very happy to see that the Program is expanding now, and we are very proud of the case management services that we're able to provide to people because seniors don't always know how to access services.

Case management is something that they all value. In fact, when they become eligible for more extensive programs, they're hesitant to give up their case manager. They want someone to be able to call and say, "arrange transportation," or "please find this for me," or "I need a certain physician, a specialist, and I am just unable to locate that person myself."

So CCPED is certainly something I advocate for, and I will continue to do so.

The Alternate Family Care Program is a program that we became involved with in August of '96. And we had some reservations about it at first,

but the State has really established that Program with many guidelines and many controls so that there is no opportunity for abuse and neglect of the seniors who agree to go and live in an alternate family care setting.

The idea of the Program is that if someone is no longer able to age in their own place that we will find a home, a home with either a professional caregiver or a paraprofessional, who knows how to assist with personal care, prepare special diets, things like that. And the concept is very good.

In reality, it's a very small percentage of seniors who really want to go and live in someone else's home. And, again, that has been confirmed in many of the committees that I have sat upon. Consumers never vote that they want to go and live with someone else. They hardly ever want to go and live, really, with their own family. They don't want to be a burden, and they like to be as independent as possible.

But for those who do elect this option, there are -- it is a labor intensive program. We have been involved, and the VNA has invested a lot of case management service and time in trying to arrange appropriate settings. You have to realize that seniors have to be matched well with the individual family they're going to live with. When you choose to marry or to go and live with someone, there are a lot of very specifics that you want clear. You don't like cats. You don't like dogs. You don't like people who smoke. You don't like people who drink. You can't make it to the second floor anymore. Therefore all of these things require, perhaps, two or three visits to the caregiver to see whether or not this match is going to work. And then, at the last minute, something happens. The senior becomes more ill or more dependent, cannot make it.

Many of the caregivers have withdrawn from the Program, with the idea that at the rate of \$40 a day, they're only being compensated at a \$1.66 an hour. And they have really given up their freedom and their life. They can't just get in their car and go visit their family in another state because they have to be concerned about this senior citizen who is now living with them.

And a large number of the people who are applying to this Program are younger disabled. And we have successfully placed some younger disabled people in alternate family care settings, but this is not really the ideal, to get a lot of younger disabled people out of nursing homes. It would be better if we could place the senior citizen, for which the Program was initiated.

Just one word about the caregivers. Not only is their compensation low, but they take a great deal of personal liability upon themselves. And we've been involved in the Program for two years, and we have just really come to realize, after meeting with insurance providers, that there is a liability to the caregiver of anything that happens to the individual living in their home is not covered under a home owner's policy. The caregiver or the sponsor agency must pay up to \$1500 a year in order to have that kind of liability coverage. And then they are still not covered if they take that client out in their car because the feeling is, by the insurance carrier, that the car insurance ought to pay for anything that happens in the car. And, of course, many seniors and disabled people don't have any more car insurance, and the caregiver's car insurance doesn't cover that person because they are then considered a business -- a business use of the car.

So we are working on that now. It is certainly another expensive cost to the Program, whether or not a sponsor agency can afford to insure, with liability, all the caregivers who are providing this service.

ASSEMBLYWOMAN MURPHY: Thank you very much, Patricia.

MS. BUCKLEY: Thank you.

ASSEMBLYWOMAN MURPHY: As you come to more information on this liability, we would hope that you would let the Department have that because that is an issue that we've been kind of wondering.

MS. BUCKLEY: Okay. I will be happy to.

ASSEMBLYWOMAN MURPHY: Thank you.

The next speaker this morning is Judith Parnes, who is the Executive Director of Elder Life Management.

Judith, good morning.

JUDITH S. PARNES: Good morning. I'm Judith Parnes. I'm a long-term care consultant and Executive Director of a small, nonprofit here in Monmouth County called Elder Life Management. We provide long-term care consultations to older adults and their families.

Today I'd like to provide testimony in regard to--

UNIDENTIFIED SPEAKER FROM AUDIENCE: I can't hear.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Move closer to the mike.

MS. PARNES: I'm going to be reading my testimony. I usually do speak extemporaneously, but given there was only five minutes, I wanted to assure that everything I wanted to say would be heard.

I'm here to address and speak to and for the most vulnerable senior citizens, what in the past was called the graying of America. We're now beyond the gray-haired Americans and are dealing with what I call the white-haired generation. This older population is individuals who are living longer and longer, needing care on a daily basis. These individuals will be facing more medically complex issues, resulting in more socially complex problems as we -- as Americans require more care.

Long life, with health, is everyone's dream. Dying without suffering is everyone's hope. Expiring in one's sleep is everyone's fantasy. We strive for a quality in living and a quality in our lives, as we, too, should strive for a quality in our dying and a quality in our demise.

As a long-term care consultant, I'm frequently called upon to help coordinate and integrate the various systems and hardships a frail, older individual and their families face. Because we're living longer and often with chronic, multiple medical conditions, programs like Medicare are seeing dramatic shifts from primarily being acute care hospital programs to one that must be able to meet people's chronic care needs.

As the Medicaid budget shrinks and the number of people needing to rely on it for increased health-care services, either by true demonstrated need or by finagling the system, it's imperative that other financial options are available.

The dramatic increase in the number of old-old -- those being over the age of 85 -- find themselves at risk for needing and receiving daily caregiving assistance. We've reached a level of medical and technological sophistication that has enabled physicians to extend and prolong our lives.

This degree of technology helps explain why those older than 85 years of age comprise the fastest-growing age-group in the United States. However, health care for the elderly potentially poses an insurmountable problem, as the cost of maintaining their health weighs disproportionately on society's resources.

Concerns surrounding the issue that for this vulnerable population any movement towards a change in practice standards will fall differentially on the elderly because of their "disposability" and their overconsumption of medical resources. In the United States, it's estimated that 10 percent of the elderly population account for more than 50 percent of health-care consumption. As people age, the problem of becoming dependent on sustained medical intervention becomes a reality. Twenty-five percent of individuals over the age of 75 need some type of daily assistance. The percentage increases to 50 percent for individuals over the age of 85.

Simultaneously, many people are fearful of being caught in this web of technology and question whether they will die with dignity or die unaware of their surroundings and as a burden to their children. As evident in Oregon's enactment of the Death with Dignity Act, society is ready to examine this issue and allow for the terminally ill, competent individual to seek medical assistance in dying.

Of significance, in the Netherlands, where assisted suicide is accepted, future cognitive incapacity, rather than pain, is a primary reason for individuals choosing assistance in dying.

When Dr. Alzheimer first recognized the symptoms of the disease that carries his name in 1906, he reported then that this type of dementia may not fit the traditional disease model, but instead be a threshold on the

continuum of aging. If his continuum model is correct, then we might all become severely demented if we live long enough. In light of present technology to prolong life, the long-term care needs of this incompetent population is obvious. With currently 4 million people being diagnosed with Alzheimer's disease in the United States, AARP projects that 9 million individuals will suffer with dementia by the year 2040.

Dementia care has become a primary concern for the legal and long-term care community. As part of the -- as part of OBRA, the Omnibus Reconciliation Act, patient determination Act went into effect in December of 1991. This legislation mandated that all Medicare- and Medicaid-certified health-care providers educate their patients on the individual rights to medical treatment decisions under State law. Facilities must ask whether a resident has executed an advance directive and must educate the staff and community on advance directive issues. The concept of advance medical directive is to uphold each person's right to make all health-care decisions and to have those decisions respected. The significance lies in the ability for this advance directive to promote an improved communication of the patient's health-care wishes when no longer able to express them.

It is my belief that most individuals with capacity for decision making would not choose to be kept alive in this last stage of life, often with a feeding tube. With the growing aging population, rising acuity levels, and technological advances, more patients, families, and providers will continue to face the quality-of-life and the quality-of-end-of-life decisions that need to be made.

To feed or not to feed may become one of the most serious ethical dilemmas our society will have to face as we enter the next decade. The greatest challenge will be to educate the public about what modern medicine can realistically accomplish and to assure that advance medical directives specifically address issues regarding artificial nutrition and hydration.

Americans have been educated to believe there is a cure for everything, including dying. The biggest challenge facing the long-term care community and the old-old and their families or for those individuals who no longer have anyone to advocate or speak for them is to have the ability to have someone monitor and advocate for their needs. Even with the increased integration of the system of health care and long-term care, the needs for this population and the need to continue to have someone recognize the needs of the individual and the family are grave.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much, Judith. And I will compliment you on having taken a very difficult subject to speak about. Thank you very much. It is one that we must think of.

MS. PARNES: Thanks.

ASSEMBLYWOMAN MURPHY: Christine Morris is our next speaker, and I understand that Sharon Anderson and Eileen Taylor, whose names were called before, are here with Christine Morris. Is that correct? (no response) All right. Well, we will move on then.

COMMISSIONER FISHMAN: Here they come.

ASSEMBLYWOMAN MURPHY: Oh, okay.

Ladies, if you would like to testify, please.

Christine Morris?

CHRISTINE M. MORRIS: Right here.

ASSEMBLYWOMAN MURPHY: Would you come up here, please, to testify.

MS. MORRIS: Am I sitting here? (indicating witness chair)

ASSEMBLYWOMAN MURPHY: Yes, please. Thank you. Good morning.

COMMISSIONER FISHMAN: Good morning.

MS. MORRIS: Good morning. Good morning, everyone.

ASSEMBLYWOMAN MURPHY: If you have written testimony-- Are you collecting the testimony? (speaking to staff)

MS. MORRIS: She has a copy of it, yes.

ASSEMBLYWOMAN MURPHY: Thank you.

MS. MORRIS: And I forgot my glasses, so I can't read it. But I know pretty much what I'm going to say.

ASSEMBLYWOMAN MURPHY: But you know what you said.

MS. MORRIS: And when -- I just wanted to say good morning and thank you for inviting me.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Closer to the mike.

ASSEMBLYWOMAN MURPHY: Yes, you'll need to pull that main microphone closer. Just pull it over closer to you.

MS. MORRIS: This one?

ASSEMBLYWOMAN MURPHY: That's right.

MS. MORRIS: Good morning and thank you for inviting me.
And I was told I have to speak for five minutes--

ASSEMBLYWOMAN MURPHY: Oh, you don't have to--

MS. MORRIS: Okay.

ASSEMBLYWOMAN MURPHY: --if you don't want to.

MS. MORRIS: Well, anyway, I'd like to say that having someone else into my home is a very unique experience. We've had three people in the past. One was 92 -- he was a 92-year-old man, and my children just loved him, and he was funny and humorous. We had another case. She stayed the weekend. She was helpful and joyful and friendly, and my kids loved her.

The third case was a hospice, which was very different. Although she was with us for only six weeks, it was a very unique experience, spiritually, for my family and myself.

I'm going to get emotional. I'm sorry.

We talked. We prayed. It was very emotional because she allowed herself to come into our home to die. And we talked about spiritual things. She allowed us to enter the porthole of her eternity. And she had her minister there, and we prayed. And being with her and holding her hand, it was a very spiritual time.

My children were rewarded with this, and I also. And -- I'm sorry, I'm not a professional speaker, but I wanted to thank Catholic Charities for allowing this for my children and myself -- to have this experience of having someone else come into our home and being that we could share this and anything that we had to offer.

Her family was also invited to our home. They stayed with us. They had meals with us. And they were just a delight, and they were very appreciative as to what we could offer and help their sister to die, into my home.

I wanted to teach my children that it was a normal part of life. Death is a normal part of life, as life is. It was scary to them at first.

But she died there, and we were just very grateful that she could die in dignity with happiness and people around that cared for her.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much, Christine.

COMMISSIONER FISHMAN: Thank you.

ASSEMBLYWOMAN MURPHY: That's quite an offering. Thank you very much.

MS. MORRIS: I had more in my paper, but I can't see it. (laughter) And I got very emotional, and I'm sorry.

ASSEMBLYWOMAN MURPHY: That's all right.

MS. MORRIS: But I wanted to wish everyone a very merry Christmas. Thank you. (applause)

ASSEMBLYWOMAN MURPHY: Christine, did Sharon Anderson and Eileen Taylor come in with you? Is that--

MS. MORRIS: Yes. Yes, they did.

ASSEMBLYWOMAN MURPHY: Sharon, would you like to testify now? And does Eileen Taylor want to come with you? (affirmative response)

We have an official timer now, too, instead of me having to suddenly look at the clock, as though I lost my mind.

You are Sharon Anderson?

S H A R O N A N D E R S O N: Yes.

ASSEMBLYWOMAN MURPHY: Good morning.

MS. ANDERSON: Good morning.

UNIDENTIFIED SPEAKER FROM AUDIENCE: Louder.

ASSEMBLYWOMAN MURPHY: Sharon, if you can pull the microphone closer to you, it may allow people to hear better. Thank you.

Eileen Taylor is here. Good morning, Eileen.

E I L E E N T A Y L O R: Good morning.

MS. ANDERSON: You'll accept a standing ovation and nothing less, right?

MS. TAYLOR: Yes. (laughter)

MS. ANDERSON: You hold out for what you deserve.

ASSEMBLYWOMAN MURPHY: Thank you for coming this morning. We appreciate it.

MS. ANDERSON: Who do you want to go first, Eileen or myself?

ASSEMBLYWOMAN MURPHY: Sharon, you may decide that among the two of you.

MS. ANDERSON: Do you want to go first?

MS. TAYLOR: You go first.

MS. ANDERSON: Okay.

ASSEMBLYWOMAN MURPHY: But do it.

MS. ANDERSON: Good morning. My name is Sharon Anderson, and Eileen Taylor resides with me and my husband and my two kids. A year ago -- sometimes you do things and you don't know. A year ago we had remodeled one of our bathrooms in our house, and my husband said, "Well, how do you want to remodel it?" So I said, "Well, the door was right by it, so let's kind of make it like for the handicapped, in case if we ever have some people who come in a wheelchair or something, they'll be able to go to that particular bathroom."

And I've always worked in an office, typing, filing, just doing -- just office chores and whatnot, and this past year because I worked for Liz Claiborne for 10 years -- so this past year I was just temping and -- so then I told my husband, last year, when we were doing the bathroom, I said, "I'd really like to just kind of stay home and watch someone or go to homes and visit people." And he was, like, "You just don't want to work, Sharon." I said, "No, no, honey, that's work, going in, watching people. That takes up a lot of time to watch people that are -- that can't get around." So then he didn't argue the issue. I won. (laughter)

So then I met-- Some friends are older women in my church, and they had told me about the Catholic Charities. So I called Ellen Rudowski. And she's just a lady full of joy. So I spoke to her, and I came into the class. And, you know, she had me come in. That's how I found out about the Catholic Charities.

So she had called me and said, "I have someone that needs to find a home, and they are -- either they'll have to go back into the, you know, the seniors home--" So I said, "I'll take her." So she said, "Yeah?" I said, "Yeah,

I'll take her." She said, "She's in a wheelchair." I said, "Yeah, but if I was in a wheelchair, I would hope that somebody would rescue me from going into a seniors home if I didn't want to." I said, "I don't want her to go into a home if she doesn't want to go, you know."

So I told my husband, and, you know, my family is kind of, like, carefree, you know. If I say this is what we're going to do, you know, that's what we're going to do. (laughter)

So they were--

ASSEMBLYWOMAN MURPHY: Eileen is agreeing with you very much.

MS. TAYLOR: Yes, that's it.

MS. ANDERSON: So they agreed. My husband said, "Oh, that's good. If that's what you want to do. Whatever makes you happy, Sharon. Whatever makes you happy." So I said that's what I want to do.

So then we met Eileen. She's just -- she's a lot of fun. She's a lot of fun. We feel like we've known her for years because she came right in. She just, like, knitted right in with us, you know. And I believe it was God's will for her to be there with us, you know. And I met her family and her sisters, and they were very nice. Eileen, you know, she wheels on through the house like, you know, everything is hers. And when she has to do whatever she wants to do, she goes ahead and does it.

And it's -- to me, it hasn't been no big change because I've had people around me all the time. So to me, Eileen is just another one to the bunch, you know. I have three granddaughters, and they come and visit, so to

me, Eileen is just another person in the house. So I don't look at it no different way. And she's--

I just want to make sure that she's happy. And she seems to be happy.

MS. TAYLOR: Yes, I am.

MS. ANDERSON: And it's not affecting us any different, you know. So anything to help. That's all that matters, anything to help or make her happy, you know. I would wish that if I -- if anything happened to me, I would wish that someone would feel the same way about me, to say, well, let me take her in and help her.

And that's the end.

ASSEMBLYWOMAN MURPHY: Thank you, Sharon.

Eileen, would you like to add to this joyishness?

MS. TAYLOR: I think it's beautiful, you know, that she feels that way. And that's exactly what I picked up from going there.

MS. ANDERSON: It's all right. Don't cry.

MS. TAYLOR: No, I get emotional.

No, really, I was in a nursing home for about -- almost five years and wanted to get out so badly. My sisters would come take me out, and that was nice, but then I would feel, why I have to go back to the nursing home? But now I feel it's so great, with Sharon and her husband and her children, and her aunt lives there also. And everyone is so terrific. Really, they're marvelous people. They've been, you know, like I would hope they would be, easy going, you know, nothing that I have to worry about. I just go there and then -- you know, it's all nice. It really is.

I mean, I used to be in a nursing home, and I used to always wish, “Oh, I wish I could get to someone else’s home,” and just to get outside, even, you know -- just to get outside at the nursing home, but it’s all closed in, you know. It’s circular, and you always feel that you can’t go anywhere, you know.

It’s very frustrating -- very frustrating. And you feel like you’re there for life, you know. I mean, I feel such freedom being at Sharon’s. Really, I mean, it’s a wonderful feeling.

ASSEMBLYWOMAN MURPHY: Well, we’re very happy you both came to tell us this because it sounds like a very good arrangement for both of you and for your families.

MS. TAYLOR: Well, thank you. I think so. For a lot of people it would be, yes.

ASSEMBLYWOMAN MURPHY: Thank you. Thank you for taking the time to come talk. (applause) It’s nice to see something working out so well.

Jean Alan Bestafka?

Have I said that right, Jean?

J E A N A L A N B E S T A F K A: That’s right. Very good.

ASSEMBLYWOMAN MURPHY: Wow, I think so.

MS. BESTAFKA: That’s why everybody calls me Jean Alan.

ASSEMBLYWOMAN MURPHY: Good morning.

MS. BESTAFKA: Good morning. Thank you for your time. I had to say that to think that this Council is charged with determining the needs 25 years from now, you better all have the wisdom of Solomon.

ASSEMBLYWOMAN MURPHY: Or the advice from people who do.

MS. BESTAFKA: Thank you.

Well, anyway, in evaluating the current and perceived needs of seniors and those caring for them, I want to address some specific services that exist today, in the hope that they will continue to exist in the future.

Home care in the United States is growing rapidly. There are 20,000 companies providing home care services to 7 million individuals in the United States. They require them because of acute illness, long-term care, long-term health conditions, permanent disability, or terminal illness.

Even though the growth in overall health-care spending has slowed-- It only grew, total health-care spending, 4 percent, in 1996, the slowest rate of growth in health-care spending in more than 30 years. We can see that home care is a growing segment of that. This rate of growth slowed because of the influence of managed care as a payment mechanism. They estimate that overall health-care spending will grow at a rate of less than 6 percent. But of the \$870 billion attributed to health-care spending, only 4 percent of that spending was in home health. And we've heard already from practically every speaker today how much people want to age in place.

I want to talk specifically about one program that allows people to age in place in this state. A very small part of the Medicaid budget has a program that's 14 years old called Personal Care Assistance. This Program is based on medical needs of clients, and it helps them to pay for certified home health aides to go into their homes and assist them with activities of daily living such as bathing, dressing, walking, and shopping.

This Program, in New Jersey, has grown from almost 5000 clients in 1993 to almost 13,000 clients in 1998. You can see that it's something that people have opted to choose in this state because it allows them to remain independent at home. And these services are provided at a greatly reduced rate. It's a waiver program under the Medicaid program, and it's provided at a rate of \$14 an hour. That's a lot less than the Medicaid home health aide rate of \$24.12 an hour. This reduced rate is possible because this Program, in general, is provided by accredited health-care service firms, licensed by the Division of Consumer Affairs and approved by the Division of Medical Assistance and Health Services.

I mention the auspices because it's a little different from those -- the Medicare-certified auspices in this state, and I know from some of the reports I've seen that there is some concern with the Medicare cutbacks that more and more people who were getting Medicare will now go into the Medicaid program.

The PCA Program has had a significant impact on the frail but independent elderly. I try to decide if frail counted as your growing population, and it certainly does. It allows them to stay at home, but because of the growth that I mentioned, from almost 5000 to almost 13,000, the Department of Human Services had begun slashing services to thousands of poor, elderly, and disabled children. They're trying to discourage use of the PCA Program, and they're trying to do it in three specific ways. I'll address them briefly.

Right now they're performing concurrent reviews, using nurses hired by an outside contractor temporarily working for the State to evaluate

patients, with the aim of cutting services. Now, do they say, "You go in and evaluate these people to cut services"? We know that's not the way it goes. But in Hudson, Essex, Middlesex, and Union County, already 1300 clients have had their services reduced or dropped from the Program completely. A couple in Elizabeth, aged 84 and 86, were dropped from the Program. He had arthritis, cardiac disease, hypertension, and glaucoma, and the wife has arthritis, ambulation problems, and falls over. In another county, a man who was a triple amputee was dropped from the Program. Another woman, in Middlesex County, died within a week of being dropped from the Program.

So this concurrent review is definitely affecting the poor -- the poor, frail elderly who are trying to remain at home.

The second way they continue to try to discourage use of the Program is to cap the rate at \$14 an hour. That's the rate they've been paying providers since 1991, when the Program was started. And they continue to require additional documents, criminal background checks, trainings, immunizations, and testing.

The third way they've done that-- And I do applaud this Program. They've developed a Personal Preference Demonstration Project that allows elderly and disabled Medicaid-eligible recipients to direct and manage their own care by giving them a monthly cash allowance to decide which services they need, and hire friends and neighbors or relatives to provide them the care.

This system, while I applaud and is greatly valued by the independent disabled person, is fraught with danger for the frail elderly. I'm concerned that PCA services are being cut, and the effects of these cuts are going to be significant. We believe that it will increase nursing home

admissions, if not deaths. Nursing home care costs approximately, annualized, \$39,000 a year. PCA home care costs approximately \$18,200 a year. If only one in nine home care clients under the PCA Program were forced to go into nursing homes, that would cost \$20.8 million a year.

The families of the people who have been dropped from the Program often have to leave their jobs in order to take care of these aging parents. And then we have the employees who are losing jobs as a result of these cutbacks in the Program. And while we believe that there should be concurrent reviews, we have real problems with the way the reviews are being done.

So in closing, I ask that this Council recommend and retain and expand the Personal Care Assistive Program and develop other cost-effective home care programs, without certificate-of-need restrictions, to provide the increasingly needed services that keep our elderly and soon-to-be-elderly senior citizens independent.

ASSEMBLYWOMAN MURPHY: Jean, is that written testimony that you have submitted?

MS. BESTAFKA: Yes.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. BESTAFKA: Thank you.

ASSEMBLYWOMAN MURPHY: Because the numbers are important for us keep. And thank you for coming down.

MS. BESTAFKA: Thank you.

ASSEMBLYWOMAN MURPHY: And thank you to Assemblyman Romano for--

ASSEMBLYMAN ROMANO: You'll notice that I haven't said a word.

ASSEMBLYWOMAN MURPHY: I have noticed that, Lou, and I--

ASSEMBLYMAN ROMANO: I held to my word.

ASSEMBLYWOMAN MURPHY: You're just wonderful.

MS. BESTAFKA: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much.
(applause)

John Barrett, from the Alzheimer's Association. John Barrett?

J O H N B A R R E T T: I would ask the committee (*sic*) to allow my mother, who is slated to speak, to speak after me.

ASSEMBLYWOMAN MURPHY: Okay. That's--

MR. BARRETT: Irene Barrett.

ASSEMBLYWOMAN MURPHY: Irene Barrett, all right. Thank you.

Irene, that would be fine.

Okay, that microphone is back on the table.

John, you need to make sure both microphones -- one is recording and the other is for hearing.

MR. BARRETT: Thank you very much for letting us come and speak to you today. I'd like to introduce myself and my mother. Our father, and husband of my mother, is a victim of Alzheimer's disease. He had early onset of Alzheimer's disease and started symptoms around 58 years old. Currently he's 69 and has spent the last four years of his golden years, shall we

say, in a nursing home. And, unfortunately, he doesn't know us anymore. He's bedridden, and he's doing okay, but it's a rough scenario for us to deal with.

The reason I asked for my mother and I to come up here was that we're a team. I was fortunate, I guess, in some crazy way, to have been going to college when my father was getting ill. My sisters, who are much older than me, had, obviously, moved out and had started their families.

My mother and I got through this whole ordeal with dealing with my father's paranoia and other symptoms of Alzheimer's disease together because we both had each other when my father would go to sleep or be in day care to talk to -- I guess to cry on each other's shoulders and to get through this. And as we say, and we're going to weed the emotions out of this, if I can do that. But if we didn't have each other, we don't know where we would be. Unfortunately, there are other people in the senior population who don't have a 24-year-old son at the time to help with their mother or father. And I don't regret it at all because it's actually something that defines my character.

When my father was in assisted living, he had soiled himself. And I wasn't quite sure how to handle that because I didn't know that the nurses and aides were responsible for cleaning my father. And I jumped right in the position of cleaning my father. And when I got home and told my mother that, she was kind of upset and appalled and started crying. And I couldn't understand her reaction. And she felt that if -- she couldn't believe that I would have to, being the son of my father, have to clean my father.

But my reaction was simply this: My father did it for me, and having a 17-month-old daughter at home, I can -- you know, I can see where

I would do it all again. And that's really where it comes from, the heart. You have to stand by each other and get through this. And also, the use of support groups were a wonderful vehicle that got us through.

My point in coming here today was to tell you a little bit about myself and the businesses of my mother and father. I myself, during college, had a moving company up in New York. I went to Queens College and worked my way through college. My mother was a professional teacher and did home study and tutoring. My father was a lawyer. He passed the bar very late in life, about 46. And I always considered him to be the Matlock of the community, the lawyer who you could always talk to for a bit of advice. He was someone who would spend his time, even though he wasn't getting paid, and talk to people and get people-- I think his biggest case was getting someone off an open fire hydrant charge up in New York, which actually now comes with some sort of criminal fine.

We had to take my father, because we didn't know what Alzheimer's disease was -- and take him down to our shore house in Lavallette, New Jersey. In doing so, we had to close down three sources of revenue: number one, my moving company; number two, my mother's teaching; and thirdly, my father's law practice. As we got down here and found that open streets and less-congested streets would provide a safe haven for him, we also realized that our income had stopped. We were there forced to take care of my dad and also spend down money that my mother and father had saved up for their nest egg for his care and health care.

In the course of a year, my mother and I had spent about \$100,000 of their nest egg, because we had done no financial planning. We

were hit with this as an 11th-hour sucker punch to the left chin. And we were forced to have to spend down money to be eligible for Medicaid and other services.

My father and mother had paid taxes all through their lives, and this was the last thing that I thought we'd have to do. We thought the services would be there for us when we needed them because we had paid into them -- I'm speaking for my father -- had paid into them all along.

And we had to go through this ordeal. We're dealing with the emotional stress of taking care of my father, plus the emotional stress of seeking legal counsel and attorneys, accountants to deal with the finances.

I'd like to turn it over to my mother, who would like to speak about the time at the health-care facilities.

I R E N E B A R R E T T: My husband is now in a nursing home since 1994 -- November '94. If any of you want to find out what's needed, I don't have to sit here and tell you because the list is too long. But I can tell you, if one of you would come with me and walk in my shoes for half a day, through the nursing home, I will not have to speak a word. You'll have your list right in front of you. It's so obvious.

There's not enough help. And I'm talking about the aides who physically take care of my husband every single day. They're not getting paid. They're overworked. They are the ones who I have turned my loved one over to because I could not handle him at home anymore. And I'm expecting these people to take care of him. I threaten them every day, "You better damn well take care of him, because I'm going to be on your back." But they do the best they can. They're lifting almost a 200-pound man. He does not understand

anything. He has to be fed. I understand there's two and a half hours personal time supposed to be given to each patient in a nursing home. It takes over an hour to feed my husband his lunch. Now, throw in the other two meals, shower, shave, dress, in and out of the bed for naps in the morning and the afternoon -- that's more than two and a half hours. He's not getting it. He doesn't even get out to the courtyard on a nice day because they don't have the time to take them out.

Yes, he is healthy. He has Alzheimer's. That's the only thing wrong with him. As far as -- I heard something earlier. I'd just like to say that I don't know of any of us who want to have our loved one pass on, although we know they have a terminal disease. We want to keep them as long as possible but with dignity. They have to be kept with dignity. The aides have to know and have to be trained how to take care of them. They do not understand anything about Alzheimer's disease.

When my husband doesn't respond to, "Come on, stand up," or "Come on, open your mouth," some of them may try to force him. He may get agitated because he doesn't understand what's going on why is he being forced to do this.

Toward the end, most of us-- I have started three support groups on my own, for Alzheimer's disease -- people who are caregivers. And I've come across so many people, and almost all of us have said that when it comes to the very end, we don't want a feeding tube. But up to that time, we want those people, those loved ones, to be taken care of with dignity.

And please, take care -- the nursing homes were set up a long time ago. The rules for nursing homes were set up a long time ago. They do not

deal with reality today. Today, over 50 percent of the patients in nursing homes have dementia or Alzheimer's. They need more. They are babies. They are infants. They can do nothing for themselves. They have to be taken care of. They need more time. You have to give them more than two and a half hours of personal time.

The nursing homes are set up to take care of people with different -- originally set up to take care of with different diseases, and perhaps those people had the cognitive ability to be able to respond to anything you -- they may have been able to feed themselves, and so on, even dress themselves to a certain degree, with a little help. The Alzheimer's patients can't do it, and yet they have to live in dignity in these places. The laws have to be changed.

Thank you.

MR. BARRETT: Thanks.

MR. MUNIZ: I just have a comment, Madam Chairwoman.

ASSEMBLYWOMAN MURPHY: Yes.

MR. MUNIZ: As a long-term care administrator and a nursing home administrator, I sympathize with your case. How old is your husband?

MRS. BARRETT: He just turned 69.

MR. MUNIZ: Sixty-nine. I mean, even more now.

MRS. BARRETT: He's in there four years already.

MR. MUNIZ: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much. Thank you very much for coming. (applause)

The next presenter is Caroline Murphy.

And do you have someone with you, Caroline?

CAROLINE MURPHY: Just for moral support.

NANCY DAY: I convinced her to come.

ASSEMBLYWOMAN MURPHY: Well, good morning. Thank you for being here. We're fine with you. You'll be fine with us.

MS. MURPHY: Okay. First of all, my name is Caroline Murphy.

ASSEMBLYWOMAN MURPHY: Okay, Caroline.

MS. MURPHY: And I didn't realize that I was a caregiver until Nancy pointed it out to me. This is Nancy Day.

I was going through a lot of changes, and I have testimony that I'll read.

In April 1994, my mother discovered a lump in her breast. The biopsy revealed that the lump was malignant, and I can remember her saying, over and over again, through sobs and praying to God and everyone else, that she was not ready to die.

Three days later, a right, radical mastectomy was performed. Being a nurse, she had cared for others who had gone through what she herself was now going through but that she had not prepared herself for the pain and fear.

In 1994, in May, my mother began the first series of chemotherapy which would continue for four years. Initially she was able to transport herself for treatments, but as they increased in strength, my aunt, her friends, and myself accompanied her to the hospital and remained at her house with her until she was able to get up and resume her regular routines.

Three years later, in October of 1997, my mother caught a break and her cancer went into remission. During her short remission, my

grandmother, my mother's mother, was hospitalized, and it was discovered that she, too, had cancer.

My mother and her sisters decided that it was best that my grandmother not know the cause of her illness, so my mother, never having told my grandmother she was ill, became my grandmother's caregiver, and I became my mother's caregiver.

Although exhausting for me but more so for my mother, we managed to both survive. On December 22nd, of 1997, my grandmother took a turn for the worse. She was hospitalized, and then it was decided that she should be told that she had cancer.

The doctor told her on December 23rd, and she refused to stay in the hospital. As my mother was too exhausted to make arrangements to have my grandmother home, I had to make these arrangements. I had to speak to the social worker at the hospital. I had to call Medicaid. I had to call Visiting Nurses, as well as care for my own household of two children, a husband, a house, and a full-time job. My life was a nightmare and my coworkers a godsend. Sleep was a thing of the past and an oddity. I had to go shopping for food, cook, make arrangements for someone else to come in and care for my mother, as my mother cared for my grandmother.

On December 24th, at 4:30 p.m., Christmas Eve, my grandmother arrived home to my mother's house. At 5:45 p.m. on Christmas Eve, my grandmother passed away.

In February of 1998, stress proving too much for my mother, her cancer was out of remission, and the doctor discovered it was spreading rapidly through her system. She was no longer able to care for herself, let alone

transport herself for the nightmare of chemotherapy, and everyone's schedules for work and recreational activities had to change, and our mission in life was to take care of my mother.

In March of 1998, it was found that she was a diabetic, and she would have to go on oral insulin. Again I had to make arrangements for her care when myself or my siblings were unable to be there. Because she had problems getting into and out of bed, a special bed had to be ordered, her room rearranged, and it was deja vu of my grandmother all over again.

My husband became both mommy and daddy to my children, and the only time I saw them was when I arrived at my mother's house, as they got off the bus there. My husband picked them up from there, and I saw them at night when they were sleeping and in the morning when they were getting ready for school.

In April of '98, my mother seemed to improve. My sisters and I wanted to spend as much time with her, and after checking with her doctor, he suggested that a cruise would be a relaxing getaway for her. However, on the third day of the cruise, she had a stroke.

On June 4th, I brought my mother back to New Jersey, where she was admitted directly into the hospital. It was discovered that a combination of the chemotherapy and the medication she was taking was causing bleeding on her brain. After being in the hospital for a week, she was being released home. I had not returned to work, utilizing whatever kind of time I had available, and only when my sister, who lives in Florida, arrived to care for my mother was I finally able to return to work.

During the day, my sister was the caregiver, taking my mother to the doctor's appointments, shopping, and cleaning. I took over after work, giving my sister a break.

On the morning of July 11th, 1998, my mother announced to my sister, "I've had another stroke." She arrived at the hospital in record time. She was placed behind a curtain. The nurse took her vitals but did nothing -- no doctor, no nurse. Even again, in the emergency room of the hospital, my sisters and I became caregivers. As we stood in the ER, behind the curtain, we watched my mother deteriorate. She could no longer speak. She could not control her brain to even write what she wanted to say. And by the time the doctor did arrive, almost three hours later, all my mother could do was blink her eyes to communicate.

She was finally hospitalized at 6:15 p.m., on Saturday, July 11th, and one week later, almost to the hour, she was gone.

After I had gone through the majority of this was the only time -- and talking to Nancy -- did I realize that I was a caregiver, and I had no knowledge where to turn to. Without Nancy's help, I don't think I would have made it through this.

Every time I had a problem, I could call Nancy, and Nancy would put me in contact with various people to help me care for my mother. But I believe that a lot of people don't realize that they're caregivers when they are. I never realized it in four years, and it wasn't until I talked to Nancy, near the end of last year, that I realized that I was a caregiver. And I think a lot more people need to realize and need assistance in realizing that they are caregivers, and they really need the support.

ASSEMBLYWOMAN MURPHY: Caroline, would you like to introduce Nancy? Give us her name and her affiliation and how you came to know her.

MS. MURPHY: This is Nancy Day. She works for the Department of Health and Senior Services. And I came to know Nancy through my job. I work with the Department of Human Services at an initiative called One Easy Link. One Easy Link is an initiative that joins the Department of Senior Services, the Department of Health, and the Department of Labor together to--

MS. DAY: Create an electronic network to communicate for clients and with service providers. And it's really a shared client database and communication that we all realize that we just don't have one problem in our life. And I think what Caroline is just pointing out that she had her children, she had her husband, she had her mother, her grandmother, and that her life needed to be addressing all of those issues at once.

And I think by the three Departments working together, we realize that we can help one family together and separately we're dealing with separate issues.

So it's interesting, even though Caroline was involved in the Department of Human Services and knows about issues, the fact that she could not identify herself as a caregiver, and it needed someone else, outside, to say, "You are a caregiver. You have needs that we can help you with," and yet here we were working for a long time, and I never knew what she was going through until this past year.

ASSEMBLYWOMAN MURPHY: We're very glad you found each other, and we're very pleased that you came today to talk to us about the fact that a service works but isn't it hard, sometimes, to access it and to understand it.

So thank you very much for that knowledge for us. Thank you.
(applause)

There is a box on the end of the table, near the transcribers. If you would leave your testimony there, we can make copies of it, so it's distributed to the members of the Council. So if -- that's what that plastic box is, at the end of the table. And we would ask you, please leave your testimony there for us to copy, so the members of the Council can reread it. It helps us. Thank you.

Oh, dear. Okay. This list is growing.

Mrs. McNally. Mrs. McNally, are you here? (no response) No?

Mr. Applegate. (no response)

All right, Ken -- and I'm going to spell the name -- Z-A-E-N-T-Z.

K E N N E T H C. Z A E N T Z: Everybody spells that name. (laughter)

ASSEMBLYWOMAN MURPHY: Well, you're going to have to help me. How do you pronounce it properly?

MR. ZAENTZ: It's Zaentz. (indicates pronunciation)

ASSEMBLYWOMAN MURPHY: Mr. Zaentz. Well, thank you very much for being here today, Ken Zaentz.

MR. ZAENTZ: Thank you. My name is Ken Zaentz. I'm the Executive Director of the Alzheimer's Association, the Central New Jersey Chapter, and I certainly appreciate the opportunity to be here this morning to

represent more than 30,000 individuals with Alzheimer's disease just in Monmouth, Mercer, and Ocean County and their over 60,000 caregivers.

You may already be aware that Alzheimer's disease is the fourth-leading cause of death among adults in the United States. It is a progressive, degenerative disease of the brain which begins slowly and insidiously and eventually robs those affected of their memory, judgment, ability to reason, and ability to function independently. Caring for someone with Alzheimer's disease is a 24-hour-a-day, seven-day-a-week job. And as you might imagine, it's filled with a tremendous amount of emotional and financial stress for the caregiver.

A recent survey conducted by the National Family Caregivers Association -- in that survey, caregivers reported negative feelings more frequently than positive feelings, reporting that they felt overwhelmed, depressed, angry. They said that what they wanted most was just a break so that they could have time for leisure activities or mental health but reported that allocating time for those kinds of things was almost impossible.

Statistically, over 70 percent of individuals with Alzheimer's disease live at home, where 75 percent of their care is provided by family and friends. That's a statistic, however, that doesn't come about always by design as we find that many caregivers are really forced to continue their 24-hour-a-day primary caregiver roles due to limited access to affordable alternatives.

One of the services that our chapter provides to people affected by Alzheimer's disease in our three-county area is a telephone help line. We receive over a thousand calls annually from caregivers who are just emotionally

and physically drained, and who are really pleading for access to affordable care options.

What they're asking us is that if we could just take away some of the stress of daily caregiving, they could concentrate on giving emotional support, love, and having a wonderful relationship with their loved one who has Alzheimer's disease. If they were just able to concentrate -- if we could take away -- give them some options and take away some of that stress, they could help continue to provide quality care for their loved one.

I just want to talk about some of the more important issues that we hear about all the time. One is respite care. New Jersey has been a leader in providing innovative respite care programs. This year's \$1 million additional appropriation for the Statewide Respite Care Program signifies a strong commitment to supporting caregivers. But even with that increase, in our chapter area, we know that there are over 130-approved applicants currently on the waiting list for that Program.

The Program needs continued, additional appropriations, as well as an increase in the service cap, which is currently \$3000 but which hasn't been increased in over seven years.

Additionally, passage of Bill No. A-1884 that seeks an \$803,000 appropriation from the Casino Revenue Fund specifically for adult day care services will permit continuation of those services to approximately 600 families in adult day care and expand access to more than 100 individuals with Alzheimer's disease.

Caregivers needing relief from assisting an individual with Alzheimer's disease in completing activities of daily living, such as bathing,

feeding, and dressing, now contract with a home health care agency, where the minimum home visit is about two hours. Caregivers tell us that because the needs of the person with Alzheimer's disease varies through the course of the disease, what they'd really like to be able to do is contract individually with those services so that they could have someone come in just to bathe or just to feed or just to help with dressing.

The other area I wanted to talk about is assistance with personal-care items. The cost of dietary supplements and incontinence products can be substantial for the caregiver. Providing reimbursement for these items, as well as assistance devices in the home, would relieve a great deal of financial stress from our caregivers.

And finally, I wanted to mention assisted living. When caregiving at home does become completely overwhelming, families want to place their loved one in the least-restrictive environment. Assisted living provides an appropriate environment for many individuals with Alzheimer's disease who do not require skilled nursing care. But because of a lack of personal funds, many families are forced to choose a higher level of care than may be necessary, and that is ultimately more expensive for the taxpayer. Those who qualify for Medicaid must be allowed greater access to assisted-living facilities.

Additionally, assisted living is also financially out of reach for many who are not Medicaid eligible. A system must be created to make assisted living affordable and provide other affordable housing alternatives so that families have long-term care options.

As you know, New Jersey has one of the largest senior populations in the nation. It is a population that will continue to grow as nearly one in

three New Jersey residents is a baby boomer. As we enter the next century, these baby boomers will move into the age of highest risk for Alzheimer's disease. Affordable care options must be created to deal with what many have described as -- Alzheimer's disease -- as the epidemic of the 21st century.

On behalf of the Alzheimer's Association, please know that our New Jersey chapters are here and ready to work with you.

And I'd like to thank you for the opportunity to be here this morning and for you to provide an opportunity for all of those voices to be heard. Thank you. (applause)

ASSEMBLYWOMAN MURPHY: We thank you very much for coming. And, Mr. Zaentz, thank you for making suggestions, too, because people who are dealing in the field quite often have something to say to change things a bit. And we do appreciate that.

MR. ZAENTZ: And what I'm trying to -- I mean, trying to relay what caregivers say to us--

ASSEMBLYWOMAN MURPHY: Correct.

MR. ZAENTZ: --because they can't all be here today, but trying to express their needs to you.

ASSEMBLYWOMAN MURPHY: That's right, and we do appreciate it. Thank you very much.

The next person to testify will be Pat Young, who has traded time with Dale Ofei-Ayisi, so they're just -- they're not new people coming in, they're just changing their slots on our list.

So Pat Young.

P A T R I C I A A . Y O U N G: Assemblywoman Murphy and distinguished Council, thank you for the opportunity to speak today.

My name is Pat Young, and I live in Bradley Beach. I recently relocated from Phoenix, Arizona. My mother, Elizabeth, is 80 years old, and she has multiple medical problems, including cardiac disease and severe rheumatoid arthritis.

During the past year, her level of functioning has dropped quite a bit. She needs assistance, transportation, shopping, housecleaning. Additionally, her gait is very unsteady and she has a great possibility of having a bad fall.

While I was living in Arizona, I was getting quite a few calls from my mother about various things, and I was at a loss of what to do. And she gave me the number of the geriatric clinic at Monmouth Medical Center, where she was getting her medical help. And fortunately for me, I was put in touch with a social worker, Robin DiNucci (phonetic spelling), with the Medical Center's Care Coordination Program.

Without their help, I really have no idea where my mother and I would be at this point because they not only were able to point me to the correct services to get help for my mother as far as home care, visiting nurse, but they actively get involved and, you know, come out to the house.

Right now my mother is having a problem. The landlord took the railing off her front stoop. The woman is a virtual prisoner in her apartment, and for a year she was fighting with the landlord, who was threatening her, "Well, if you don't like it, get out." "Don't call us, or we're going to have you arrested," I mean, silly things like this, and Ms. DiNucci has finally arranged,

after much badgering and everything else, to finally get someone to put this railing in for her so that she'll be able to get out of her apartment and feel like a person again.

Currently there is no funding or reimbursement for the Care Coordination or nonmedical case management. Unless seniors have significant medical problems, they do not qualify for home health care. And they are severely at risk and need guidance through the maze of services and options available. I'm sure even we would have a problem getting through this maze. I know I would have.

So I would encourage the Council to support and fund programs, such as Care Coordination that not only provide information and referral services, but they do participate in an active role in securing these resources to help keep someone in their home for as long as possible.

I'd just like to thank you all for this time to speak to you.

ASSEMBLYWOMAN MURPHY: Thank you very much for being here, Ms. Young. Thank you. (applause)

The next speaker today is Mr. Bryne, B-R-Y-N-E. Am I pronouncing that right? Is it Bryne or Burn? (no response) Well, if he isn't here, I guess it's not as important.

Gloria Zayanskosky.

And you are here today wearing two hats, Gloria, I hear?

G L O R I A Z A Y A N S K O S K Y: Yes, how did you hear that?

Good morning, everyone. My name is Gloria Zayanskosky, and as our lovely Assemblywoman said, I'm here wearing two hats today. I'm here wearing my professional hat and also my personal hat.

My professional hat is I am a certified assisted-living administrator, currently working as a Special Care Center Manager for Marriott International, which you know operates several assistive living residences in the state here. But I'm also here wearing my personal hat, which is a concerned member of the Alzheimer's Association and also as a former caregiver for many years to someone in my family.

And the concern that I share under both hats is that there seems to be a lack in the long-term care industry of recognizing that caring for people with Alzheimer's is a specialized skill and service. Caring for someone with Alzheimer's requires an understanding of the disease process, what the symptoms are, and how to intervene. I've had the pleasure of working in long-term care for the last 15 years and have had the opportunity to set up many special care centers, both in skilled nursing facilities and assisted-living facilities.

The one key component that I believe that you need for a special care unit is special staff. And this doesn't require just special people, but in order to have them trained appropriately for the care of these people.

Right now, a CNA, who works in a nursing home or an assisted-living residence, must pass the State exam that requires they can demonstrate the basic skills to provide personal care. Also now, under a new program, certified nursing assistants can demonstrate basic skills and be certified to pass medications -- administer medications on units. However, there is no requirement for training for people to work with Alzheimer's. They don't have to demonstrate any basic knowledge of this disease, which is a great concern.

I personally work for an organization now that has an internal policy that requires we give additional training to people who work on special care units; however, this is not an industry standard by any means. And I am concerned that without some kind of governing authority-making provision to make this a policy, this will not happen.

So today I'm here to ask -- to recommend that there be some provisions made for some kind of regulation or at least advisory standard. Currently, in the nursing home industry, a certified Alzheimer's unit does have a regulation requiring some training. However, in assisted living, there is none. There are no provisions.

And as you know, the assisted-living industry is booming in our state as we speak, and more and more of the industry providers are advertising special care units. So this is a great concern to me that there is no provision made.

My professional hat says, right away, if you're going to implement the regulation, who's going to pay for it, of course. But having worked in the industry, I can tell you that this would not be a costly initiative, either to the State to monitor or to the industry to provide. So it is something that would benefit everyone. It would most definitely improve the quality of care for the residents living in these facilities, and also give the families, who care for these people, peace of mind, knowing that the staff has been appropriately trained, and therefore, I think the benefits are immeasurable.

ASSEMBLYWOMAN MURPHY: Thank you.

Gloria, as she has noted, is a special care manager for the senior living services of Marriott Corporation. As we all know, Marriott does a great deal of housing for seniors, in particular, in this state.

Since she has this second expertise, which she is offering to speak to today, are there questions from the Council on the Marriott structure of housing?

Would you like to just briefly talk about the levels that Marriott is developing in terms of the caregiving for seniors in the state?

MS. ZAYANSKOSKY: Yes. Right now Marriott has approximately about 112 senior living communities across the country. We currently operate 8 in the State of New Jersey, here. They are primarily all assisted-living residences. The majority of the 8 in the state here have special care units within them. We do have one that I know has a skilled nursing facility and another that we consider a full living service community.

But within our traditional Brighton Gardens product or community, there is assisted-living residences, which is usually about 90 units, and then a special care unit, which is about 24 units.

ASSEMBLYWOMAN MURPHY: What's the special care?

MS. ZAYANSKOSKY: Special care is a unit which is totally designated for people with memory loss or illnesses relating to dementia, primarily Alzheimer's disease. The unit is usually designed very small to help people with Alzheimer's to be more structured so that they have the caring and the direction they need.

Our assisted-living residences offer people who might be in the very early stages of dementia but that may not be their primary problem. They

usually are there because they need some assistance in other areas of their activities of daily living, primarily maybe with bathing, medication administration, preparing meals, help with laundry. And within that structure, the assisted-living structure, we offer five levels of care right now.

In each level, there's a cost associated with, and the level is determined by how much help they need. It's determined within minutes of care.

MS. GREENBERG: Can you tell us something about the costs, please?

MS. ZAYANSKOSKY: The cost for some families is very prohibitive. The average cost at a Level I, which would involve about 40 minutes of care a day is, about \$2300.

MR. MUNIZ: Out of the 1500 slots of Medicaid, how many slots does Marriott have?

MS. ZAYANSKOSKY: We just recently became a provider, so to my knowledge, we haven't admitted anyone under CCPED, but we have become a provider and are anxious to participate in the Program. We do see a need for it.

MR. MUNIZ: It's very important. Actually, I'm very interested in it.

MS. ZAYANSKOSKY: Yes.

ASSEMBLYWOMAN MURPHY: Gloria, we may call upon you to come in your professional capacity to speak to the Council at a later date. I do hope that you will oblige us.

MS. ZAYANSKOSKY: It would be my pleasure to help in any way. Thank you.

ASSEMBLYWOMAN MURPHY: My goodness. It's very nice to meet you. Thank you so much for being here today. Thank you. (applause)

MS. ZAYANSKOSKY: Thank you.

ASSEMBLYWOMAN MURPHY: Let's see, we spoke about Mr. Byrne, who was not here. And we're moving on to Ellen Rudowski, who is Program Coordinator, Catholic Charities, Boarding House Issues, Department of Health.

Good morning, Ellen.

ELLEN RUDOWSKI: Good morning.

ASSEMBLYWOMAN MURPHY: Your name was mentioned before by someone else here.

MS. RUDOWSKI: Oh, I heard. I heard. They thought I was full of fun.

ASSEMBLYWOMAN MURPHY: You have some very delightful and delighted caregivers and care receivers.

MS. RUDOWSKI: Yes, it's quite a rewarding program. I am the Program Coordinator for Catholic Charities, but I do want to point out that we do have a very exciting relationship with Community Medical Center and Kimball Medical Center. So although Catholic Charities is a sponsor agency, it was developed with this collaborational agreement, and the social worker that assists me with monitoring the client-caregiver relationship and placement comes from Care Coordination of Community Medical Center, and we're real excited about that.

I know that you've had an overview of adult family care, so I'm going to skip the beginning part of my testimony, which I'm sure you're pleased. But I do want to address some benefits, because they directly impact the issues that I need to bring to your attention in regard to boarding home licensure.

In regards to the benefits and who benefits from the Program, it's really a winning proposition for all individuals involved. You saw clients -- like Eileen, okay, clearly has benefited. She is able to gain the ability to remain independent as long as possible in the community. The client-caregiver relationship is monitored, as I said, regularly, by myself as a registered nurse, and Tracey Torrey (phonetic spelling) of Care Coordination, as the medical social worker.

The cost of a Catholic Charities Adult Family Care Program is \$1745 a month, which is less than a third of the cost of nursing home placement. With the focus of self-sufficiency, our Program documentation has been reflecting an ongoing improvement with level of functioning of the clients that we have placed on a weekly and monthly basis. So we're real pleased with that.

Caregivers, already with a desire to help others, gain training and skills necessary to assist clients. They receive financial reimbursement for room and board and personal-care services, as well as satisfaction that comes from knowing that they've made a difference in the life of another one.

The financial compensation currently is \$1230, under the Catholic Charities Program, and the community benefits, as well. This Program offers home health aides, many of whom do not earn \$1230 a month, an opportunity

to stay at home to raise their children or care for a family member -- like Christine, she has a husband at home that has had two strokes -- relieving them of the costly burden and often worrisome issues revolving around child care and transportation to and from work. It's been very surprising to me the number of home health aides and nurses aides that I meet that take public transportation across county lines just to fulfill occupational commitments.

National statistics also reflect a high percentage of care providers are between the age of 55 and 75. Thus, these individuals, adult family care is able to help them supplement their income and continue to do what they've been gifted to do, and that's caregiving.

The other population I'd like to talk about is loved ones. Those of us who are members of the sandwich generation are faced with the question of how are we going to care with our parents. Our Respite Program, under adult family care -- because it could be long-term placement, like Eileen, or maybe a respite stay -- has been a godsend for many of the families. Gene's family needed time to be alone to reflect on the needs to rekindle their own spirit and develop an openness for alternative referrals for Gene's care.

Along with my testimony that I have given you, I have included and will not discuss today a copy of a case story, and it's about when Gene was placed with Christine, okay. There is a color photo. I love the color photo, because you can see the twinkle in Christine's eyes. By the time Gene left, there was a twinkle in her eyes, as well.

And Helen's daughter, whose husband was going out of state for a serious medical intervention. Our Adult Family Care Program offered her

peace of mind that 85-year-old, visually impaired mom and physically handicapped mom would not only be safe, but would be healthy and happy.

Taxpayers benefit because Adult Family Care expands to help continuum options at a more costly rate. Sue Watson, of the New Jersey Department of Health and Senior Services, our great director of Adult Family Care, reports the fact that AFS can care for three individuals at the cost that it is to have one individual in a nursing home setting.

Municipalities benefit as these individuals maintain the integrity of an established community. These residents create new business opportunities for local merchants. For instance -- Eileen is probably going to growl when you hear this -- she's scheduled to be evaluated by the New Jersey Department of Vocational Rehab. That's the good part. We have worked real hard. Actually Tracey Torrey, the social worker at Care Coordination, has worked real hard with vocational rehab. They will donate a dictation computer, give her extensive computer training, and in return she will fulfill a part-time work assignment.

And so, Eileen, you'll be a taxpayer. (laughter)

That's the part she doesn't like.

With this overview of the adult family care being said, I really come forward to you to discuss issues that have been some roadblocks not only for Catholic Charities, but for all the sponsor agencies. And the first one is the Medicaid waiver caps. There are two caps. In particular, there's a medication cap of \$112 a month. Presently, legislation has been drafted to address the medication cap and the boarding home license, and that's why I'm here today.

I just had a client that was 86 years old being evicted from her home, and she wound up in an emergency church shelter because she was on 18 medications, well past the \$112 a month cap. The great thing about that is we were looking at placing her in a home with a physician's assistant, so what better way to be able to really look at the need and the necessity of those 18 medications and be able to medically monitor, if the doctor chose to adjust her medications in any way, okay.

The other thing is that there's a \$225 cap for ancillary services, and this covers such therapy as speech therapy, physical therapy, occupational therapy, dialysis. If we all believe, statewide, that adult family care or alternate family care is going to be a true alternative to nursing home placement, then the Medicaid client needs to have access for those same services, okay -- that medications that are covered in the nursing home need to be covered in the home basis. If I'm a client in a nursing home getting dialysis, I should be able to have those services available to me in a home setting.

ASSEMBLYWOMAN MURPHY: Joan, I'm afraid that the--

MS. RUDOWSKI: Oh, it went up (referring to timer), and I didn't even talk about boarding homes. I'm sorry.

Well, real quick, the legislation currently states that you can have three individuals in your home. If the second client stays longer than 90 days, then you need to have a boarding home license. Boarding home licenses are a very sensitive issue, especially in Ocean County.

ASSEMBLYWOMAN MURPHY: Right.

MS. RUDOWSKI: And I've had scenarios where it's been two sisters that want to live together or neighbors that have been living close to each other for 30 years.

ASSEMBLYWOMAN MURPHY: We do hear this issue.

Commissioner Fishman.

COMMISSIONER FISHMAN: I have a question I wanted to ask you, Ellen--

MS. RUDOWSKI: Sure.

COMMISSIONER FISHMAN: --which is about recruitment. Where do you find your most promising recruits to offer this kind of care in their home?

MS. RUDOWSKI: Clients. You're talking about recruiting clients or care providers?

COMMISSIONER FISHMAN: Care providers.

MS. RUDOWSKI: The care providers. We were very fortunate that Community Medical Center launched an impressive ad campaign for three months, and that brought out, I would say, probably 150 care providers.

I have 68 currently interested in the Program and probably about 20 through the screening process. The \$1230 a month, only being able to take one client into your home really hinders that. Some people need to work part-time. They can't live on \$1230 a month, so if they were able to take two or three, without that boarding home license, then you would be able to not have to work.

COMMISSIONER FISHMAN: So is it your impression that if that impediment were removed, which we're working on, that you would be able to recruit many more caregiving providers than you have now?

MS. RUDOWSKI: Yes.

COMMISSIONER FISHMAN: So you don't see that as a problem?

MS. RUDOWSKI: I don't see it as a problem. You know, people-- You speak of boarding homes, and that's it. You know, it's in the newspaper every day. So people are not at all willing to go to their towns and even further that.

COMMISSIONER FISHMAN: Where is your office?

MS. RUDOWSKI: Water Street, next to the main post office, in Toms River.

COMMISSIONER FISHMAN: In Toms River. So what area are you covering? Are you the only Catholic Charity that is doing this, or is this--

MS. RUDOWSKI: Yes. Yes, we're the only Catholic Charities doing that. We're licensed in Monmouth, Ocean, Burlington, and Mercer. I have care providers in Burlington, Ocean, and Monmouth -- clients placed in Ocean.

COMMISSIONER FISHMAN: Thank you very much.

DR. ROBINSON: I just have one question, also. Do you find that it's tough to make a caregiver-client match? We heard testimony to that, in fact, earlier.

MS. RUDOWSKI: It's challenging. That's the word. A lot of times people call me. The question always is, "How often can I have a client

into my home,” or “How often -- how quickly can you get my uncle into the house?” And it’s more than just having beds and having clients because it’s, “Who’s allergic to the dog,” “Who’s allergic to the eucalyptus, and my great grandmother owned a euclyptus company.” I mean, it’s-- I’ll tell you, trust me, Murphy’s with me every day, you know, you know. It’s just amazing. Things that you would never think could ever happen, you know, happen. And it’s those little things--

COMMISSIONER FISHMAN: We have a different Murphy’s rule on this committee (*sic*). (laughter)

MS. RUDOWSKI: Oh, do you. I’m sorry. No offense, and I would love to have you with me anytime.

ASSEMBLYMAN THOMPSON: In addition to the \$1230 a month that you say they get, are additional funds supplied to cover costs such as, you know, groceries and etc?

MS. RUDOWSKI: No, that’s included in the \$1230.

ASSEMBLYMAN THOMPSON: That comes out of the \$1230.

ASSEMBLYWOMAN MURPHY: You mentioned \$1075 a month. What is that for?

MS. RUDOWSKI: The \$1745 a month is the cost of the Program, okay. The care providers are reimbursed \$1230 so that there is a \$498 difference that goes to Program costs: my visits, Tracy’s visits.

COMMISSIONER FISHMAN: Ellen, the care provider would also get some additional funds from the person that they’re providing care to. Is that right?

MS. RUDOWSKI: The way that our billing is set up, all the funds go through Catholic Charities, so that room and board, the fee that you're speaking of -- the \$452.75 -- the client pays Catholic Charities, we pay the care provider.

COMMISSIONER FISHMAN: So what's the net that a care provider makes, per month?

MS. RUDOWSKI: \$1230.

COMMISSIONER FISHMAN: That's including the--

MS. RUDOWSKI: That's including the \$452.75, okay. So the client totally pays \$1745. The caregiver gets \$1230. We get the \$498. And our respite fee is \$75 a day. Elsewhere in the county, it usually starts at \$150. Catholic Charities' mission statement is to elevate human suffering for all clients and families, and we see that there's a great need for respite relief.

It's not necessarily what's -- that it exists or doesn't exist, but it's what's available and the cost, is what we have seen.

ASSEMBLYWOMAN MURPHY: Thank you very much, Ellen. We appreciate your accounting of the Program. Thank you. (applause)

MS. RUDOWSKI: Thank you.

ASSEMBLYWOMAN MURPHY: Joan Itzkowitz, from Morganville, New Jersey, a caregiver.

Good morning -- good afternoon, I guess -- almost, almost.

JOAN ITZKOWITZ: Okay, good morning, still. I am here today with no prepared text. I'm going to be speaking extemporaneously. I am here to represent-- I am a caregiver for my parents. My father is 89 years old and in the terminal stages of dementia, capable of no self-care whatsoever. My

mother is 80 years old and has a myriad of medical and, I guess, emotional problems, as well. They live with me and my family. I work full-time, out of the home, and have arranged for home care for them in my home.

I have lots of concerns. I have lots of issues, and I'm going to speak.

If I chose to put my parents into a nursing home or some sort of institutional facility, their limited amount of resources would be used up in a very short period of time. But because I have chosen to keep them with me in my home, I am unable to get help for them. And this upsets me a great deal. The priorities of this country and this State are somewhat distorted, in my opinion. It certainly would benefit every taxpayer sitting in this room and outside of this room if I could help my -- if I could get help, not just for my parents, but everyone in my position.

Additionally -- I'm going to be pretty brief -- I have another concern. When I have called various State, county agencies, there is no streamlining of efforts to have me-- I received information from Family and Children's Services, Department of Health and Senior Services, Office on the Aging. There are too many different agencies to deal with, who might be able to provide some assistance, and the coordination of efforts just is not there, from what I've been able to observe.

This disturbs me a great deal, too. It's not-- I'd like one supermarket to shop in. I don't have time to go around and hunt from store to store.

I thank you for allowing me the opportunity to speak to you and bring up these two issues, which I feel are concerns.

ASSEMBLYWOMAN MURPHY: Joan, may I just ask, what county is Morganville in? I no longer feel qualified-- (laughter)

MS. ITZKOWITZ: It's in Monmouth County.

ASSEMBLYWOMAN MURPHY: It is in Monmouth?

MS. ITZKOWITZ: Yes, it is.

ASSEMBLYWOMAN MURPHY: If New Jersey EASE is the program in Monmouth County, and I thought that it was, New Jersey EASE is exactly the coordinating program, is it not, that you are seeking?

MS. ITZKOWITZ: I don't know. What is New Jersey EASE?

COMMISSIONER FISHMAN: All right. There we are.

ASSEMBLYWOMAN MURPHY: It's the one number--

MS. ITZKOWITZ: The one-stop shopping.

ASSEMBLYWOMAN MURPHY: --that is the one-stop shopping. It is presently a program in 13 of our 21 counties and was two years ago -- three years ago, I believe -- a pilot program in my county of Morris that has been growing through the state.

Yes, ma'am.

MS. STRACK: (speaking from audience) The telephone number is 1-800-246-9292.

MS. ITZKOWITZ: 246--

ASSEMBLYWOMAN MURPHY: 9292 -- good girl. That's exactly right. There's the Director of Aging.

COMMISSIONER FISHMAN: But, Joan, I--

I think what Joan illustrates is the fact that while we've got a system in place and we're proud of what Monmouth County has done, getting

the word out to people who need it -- and you're obviously one of the more informed folks out there -- you're not familiar--

MS. ITZKOWITZ: And I know nothing.

COMMISSIONER FISHMAN: That just shows what a lot of work we've got to do to make sure that people know how to find their way to that supermarket.

So I thank you for raising that point.

MS. ITZKOWITZ: And also the fact that, why do I have to feel that I will have to put my parents into a nursing home in order to get--

COMMISSIONER FISHMAN: We hear you. We hear you.

ASSEMBLYWOMAN MURPHY: Thank you very much for coming. It's an awareness that we constantly need to have spoken about.

COMMISSIONER FISHMAN: Joan, let me just ask you one other question, because one of our big challenges is to get the information about one-stop shopping in a place where people will encounter it. And recognizing that we don't have a multimillion dollar advertising budget, what are one or two of the most strategic places where you might have come across that number?

MS. ITZKOWITZ: Phone book.

COMMISSIONER FISHMAN: Phone book. What would you have looked under?

MS. ITZKOWITZ: Social services. Social services.

ASSEMBLYWOMAN MURPHY: What about doctors' offices?

MS. ITZKOWITZ: My father can't go to a doctor's office. He's totally bed bound. I have to bring the doctor in. That's another issue. I mean, there are lots of other issues I could bring up.

ASSEMBLYWOMAN MURPHY: But I'm wondering, do doctors have this kind of information in their office so the doctor would have thought to give you these.

COMMISSIONER FISHMAN: We're working with the Medical Society, but it's -- it takes awhile.

If you have other thoughts about how we might get that information out -- and I'd welcome anybody who speaks to offer advice on that point, since it's so critical.

MS. ITZKOWITZ: I worked five days this week. This is the sixth day. No, I can't think of it right now.

COMMISSIONER FISHMAN: Okay. Fair enough.

ASSEMBLYWOMAN MURPHY: Thank you.

COMMISSIONER FISHMAN: Thanks a lot.

ASSEMBLYWOMAN MURPHY: The next speaker, Dale Ofei-Ayisi. Have I massacred that? This is Murphy's law in operation today. I can tell that.

Dale, perhaps when you sit down, you'll straighten me out.

DALE OFEI - AYISI: Don't feel badly, please. Everyone -- my name is a little difficult. It's Dale Ofei-Ayisi.

ASSEMBLYWOMAN MURPHY: Ofei-Ayisi. Thank you very much, Dale.

MS. OFEI-AYISI: Thank you. And good morning, ladies and gentlemen. I appreciate the opportunity to be able to speak to you this morning.

I, as Gloria Zayanskosky, also wear two hats. Professionally, I'm a licensed clinical social worker, and I work in the GEMS Program, which is a Geriatric Evaluation and Management Service, which is part of the Senior Health Services at Kimball Medical Center. I'm also a volunteer for the Alzheimer's Association, on its Board of Directors and, as such have been very honored to work with a lot of tireless workers like Mr. Zaentz and like the Barretts and like Mr. John Dill and also worked with a number of caregivers.

My role, in particular, is working with Alzheimer's patients and their caregivers. And I've really been struck by a lot of the testimony I've heard so far. And as a backdrop to that, I'd just like to talk about one particular segment of patients and caregivers that I feel whose needs are important to address, and that is culturally diverse patients and their caregivers.

ASSEMBLYWOMAN MURPHY: Thank you. We were discussing that this morning as being something we have not yet heard. Thank you.

MS. OFEI-AYISI: You're very welcome.

As you may know, New Jersey has gradually become one of the most culturally diverse states in the union, and as I understand, it's probably one of the five most popular destinations of new immigrants. Included in these immigrants are seniors, who, as their American counterparts, age in place and develop chronic illnesses such as Alzheimer's disease. They require

community services, home health services, and also health education that promotes their safety and optimal functioning in their environment.

I must say -- I'd like to step back a minute and say, as well as my professional hat, I also have a personal hat. I am a caregiver, along with my mother, of my grandmother, a wonderful, wonderful woman who worked very hard all of her life, but who, like many seniors, is experiencing several chronic medical illnesses, one being dementia. And she lives with us. So day to day, not only professionally, but personally, I'm faced with this issue of dealing with long-term care and responding to the needs -- not only her needs, but the needs of my mother and also of myself, a working caregiver.

One of the things that I find with many culturally diverse groups is that oftentimes they are faced with substandard access to proper care because of factors such as language barrier, financial impoverishment, and a lack of sensitivity and awareness of their cultural traditions and beliefs and values that influence their response to health care on the part of our health-care providers. Even basic things like information in their native language, even in Spanish, which really is -- it's probably the second most used language here in the United States, it's still a common problem, believe it or not.

Likewise, those ethnic seniors that have been born in the United States, such as my grandmother and other African-Americans, grew up in a world where limited economic resources, poor access to health care and other services was a way of life because of the impact of legalized segregation and institutionalized racism.

The mistrust of existing health-care resources was fostered by treatment that was often dehumanizing and often exploited people, such as the

infamous Tuskegee experiments. And today people are still very afraid of things like signing up for organ donation or experimental drug programs. There's still a lot of mistrust and a bridge that has to be crossed. The result is that these seniors enter the health-care system with advanced, multiple chronic illnesses, with little resources with which to fight them, increasing the stress on their often overwhelmed caregivers.

Even institutional care, which sometimes, for the poor, is the most viable option for those who are alone, that need 24-hour care, because it's the only thing that Medicaid will provide full coverage for, for many cultural groups, this is not an acceptable option because in their culture they perceive nursing home placement as abandonment, as many other mainstream groups do. But particularly in their culture, it's abandonment. It's completely unthinkable, even in the cases when there's extreme stress and burden to the family caregivers.

In my professional experience and personal experience, I find that families -- these families, as well as mainstream American families, want to care for their loved ones until the bitter end. They want to hold on to them, regardless of their diagnosis, regardless of their condition, and give back to them what they've been given over the years. And oftentimes, those people are prevented because there's a lack of resources, such as you've heard in some of the previous testimony.

I'd just like to mention the following steps -- things that I would like to see this Council take a look at in terms of looking at expanding elder care services.

One is supporting existing programs that target those populations, through outreach efforts, and creating incentives to broaden these services or build new programs. Outreach is defined as going to -- like the mountain going to Muhammad -- is like going into senior buildings, going to churches, which may be another way to get the word out about different programs, like New Jersey EASE, that are very important institutions for many cultural groups. That's been shown, over and over, to be one of the most effective ways of reaching people that haven't been reached in the past. And those efforts should be -- again should be bolstered and supported.

There's a program through the Care Coordination Program at Kimball, called the MORE Project, which is a multicultural outreach program that since 1992 has been reaching out to African-American and Hispanic seniors, those that previously had not been identified by anyone, living in substandard housing, using kerosene in this day and age, making decisions like whether or not to get my medicine or whether or not to eat this month, or whether or not, you know, to even go to the doctor, feeling really dehumanized when they go to the doctor, not having their questions answered. Those people have been reached out to through programs like MORE, which I must say, again, was sponsored by the Ocean County Office of Senior Services.

And those little programs, grassroot programs are wonderful efforts that should be promoted throughout the state, and we don't have to reinvent the wheel. There are other programs in other communities throughout the country that provide services to Alzheimer's patients and their families and patients with other chronic illnesses of different ethnic groups that we could use for guidance to establish models providing money for research or start-up

funds to build incentives for hospital-based or community services to develop what I call culturally competent elder care services, for example:

Providing grant money specifically to develop health education literature, videos, tapes in Spanish or other languages that would be readily available not only to hospitals, but to church groups and others who again are reaching out to these people; developing -- providing technical supports, developing like a statewide clearinghouse of information open to the public to provide access to information on working with elders of specific cultural, ethnic or racial groups; providing incentives or mandates for development of culturally sensitive training programs for employees of those services receiving State funding. This could include provisions of training material for those programs attempting to do cultural training.

Again, at Kimball-- I just wanted to mention one quick thing. These programs don't have to take a lot of massive effort. There could be volunteers -- volunteer employees at facilities, like Kimball did, can get together and help develop a cultural training program to teach other employees how to reach out to people like -- we did one that reached out that talked about how to work with African-American, Hispanics, and Orthodox Jewish groups. And it was very successful. We were able to train 1400 employees. It took time, but people were very interested and involved. So it doesn't take a lot of money, but just a lot of interest and time and effort.

ASSEMBLYWOMAN MURPHY: If you have models on any of those programs that you would like to share with us, we would be very, very pleased to receive them.

MS. OFEI-AYISI: Certainly. Thank you very much for your time.

MS. GREENBERG: What was the name of your program, the
MORE --

MS. OFEI-AYISI: It's through the Care Coordination Program,
it's M-O-R-E. It's Multicultural Outreach and Resources for the Elderly. It's
a part of the programs that are sponsored by the Ocean County Office of
Senior Services.

MS. GREENBERG: Thank you.

MS. OFEI-AYISI: Thank you very much.

ASSEMBLYWOMAN MURPHY: Thank you. (applause)

The next presenter is Harriet Jones. Harriet Jones? (no response)

Kathy Bornemann. Kathy Bornemann? (no response)

Joe Riordan. Joe Riordan?

JOSEPH RIORDAN: Good morning, Assemblywoman and members
of the committee (*sic*).

ASSEMBLYWOMAN MURPHY: Thank you for being here.

MR. RIORDAN: And thank you for your efforts in this
enterprise. I'm going to be a little disjointed, but you just have to bear with
me.

ASSEMBLYWOMAN MURPHY: Okay.

MR. RIORDAN: My name is Joe Riordan -- Joseph Riordan. I'm
a long-term advocate for worthy causes, including health care generally, with
a major focus on senior care.

I'm presently living with my wife of 55 years in a town house in
East Windsor. Val at this point is a multi-enfarct-dementiation. (phonetic
spelling) We keep her comfortable and offer her some quality of life with the

help of a full-time live in home health aide, registered. The cost is \$40,000 a year. This includes two days of where we put her in day care, which gives her a change of atmosphere and is good for her, and she adjusts well to it.

Doing this for my wife has made me cognizant of the fact that many seniors should have an appropriate way to enjoy the quality of life, even though they may not be in a position to pay the total costs.

You probably have seen the Department's publication. I would hope you've all seen it. It was titled "What Long-Term Care Setting is Best." It certainly covers all the options. According to that publication, 85 percent of nursing home residents are single or have outlived their spouses, and 50 percent have no living children. It's reasonable for me to believe that some -- at first I put in a percentage, but I decided not to do that -- that some of these people could live in a different setting.

Where are we failing? Is it that it is easiest for the assessor to recommend nursing home care, or are the options not available? Nursing homes, of course, are the proper setting for some patients.

My personal preference would be assisted living. The existing facilities are well beyond the means of most seniors. Marriott is a \$40,000 a year operation, I believe.

There are, of course, many other options contained in the Department's guide, which should be considered.

I'd like to quote a few things that I have accumulated in my time in service. An organization called the Urban Institute has issued a report called "Long-Term Care for the Elderly: Profiles of 13 States." New Jersey is one of them.

People are shaking their heads. They have seen it. I'm going to quote from it, because I think it's worth hearing.

"Long-term care for the elderly is a priority of the New Jersey Medicaid program. Despite the prominence of institutional care, the State's policy for long-term care for the elderly in the near future includes expanding the availability of home- and community-based service through the Medicaid HCVS waivers.

"Future budget pressures will mean more efforts to reduce payment rates in both nursing homes and home health care and tightening eligibility for admissions into nursing homes. The State is expected to use any savings in nursing facility expenditures to increase the availability of community-based services.

"There is considerable concern" -- I say this, friends, tongue in cheek -- "over the State's lack of sophistication in this area. It is hoped that the new Department of Health and Senior Services will enhance long-term policy development."

Another thing I'd like to mention from this report:

"New Jersey has made no significant efforts to expand private, long-term care insurance; although, a task force on that subject is scheduled to meet in 1998. Transfer of assets to obtain Medicaid eligibility is considered a major problem for the Medicaid program."

I'm happy to say that I'd be willing to put a bumper sticker on my car that I'm spending my children's inheritance. I know if I needed more, they'd help me.

“However, many elected officials are not particularly supportive of tightening Medicaid transfer of assets policies.”

It’s a quote from the report, Assemblywoman. Don’t blame me.

ASSEMBLYWOMAN MURPHY: I don’t.

MR. RIORDAN: “The State operates a small estate recovery program that has recovered \$2.2 million in 1994, 0.3 percent of Medicaid nursing home expenditures from the estates of deceased residents -- recipients.

“New Jersey has not engaged in major efforts to maximize Medicare reimbursement; although, it has mandated that nursing homes become duly certified by Medicaid and Medicare. This certification enables nursing homes to bill Medicare as the first payer and then Medicaid as a second payer for any remaining services.”

While I’m quoting, I’d like to quote one other thing.

ASSEMBLYWOMAN MURPHY: Mr. Riordan.

MR. RIORDAN: Yes, ma’am.

ASSEMBLYWOMAN MURPHY: My little timer here has gone off, so I won’t stop you, but I will caution you that--

MR. RIORDAN: I’m getting near to the end.

ASSEMBLYWOMAN MURPHY: Okie dokie. Thank you very much.

MR. RIORDAN: I’m going to quote the Governor.

ASSEMBLYWOMAN MURPHY: Okay.

MR. RIORDAN: “Government should only do what individuals can’t do for themselves and that government decisions should be made as close to the people that they affect as possible.” Christine Todd Whitman.

This book is available. If anybody wants to know how to get it, I'll give them the information.

I would like to just take -- one other -- few remarks in closing.

There are things happening. I heard, in the past few days, of an ecumenically sponsored, assisted-living facility in Sparta, which charges on a sliding scale. There also was, in that area, a home health agency treating clients using telemedicine. Telemedicine is new, it's hot, it's good. It's got a lot of possibilities, maintaining contact by sophisticated television. Information on the concept is available.

One other thing I'll bring up. Some groups are looking at a program called PACE. PACE is-- I'll give you the acronym. The acronym is PACE, and the name is the Program of All-inclusive Care for the Elderly. The people in the Department know of this. There are some efforts being made, here and there, to try to put it in place. It's a wonderful concept. It's a wonderful concept.

I know you heard a lot of good, good things today. And I know how busy you folks are with kind of menial tasks like managed care problems, but I wish you luck and well, and I hope all of you will make every effort you can to make recommendations to the Governor along the lines you've heard from lots of people today.

Thank you very much.

ASSEMBLYWOMAN MURPHY: Thank you, Mr. Riordan.
(applause)

And I will say that we are here. We were created and we are here because we have a governor who wanted us to do this. And this was her

concern, and this is why this Council was convened and why we have the great support of the staff that is here with us to make it possible.

COMMISSIONER FISHMAN: Madam Chairman, I want to acknowledge what a great advocate Joe Riordan has been, over the years, both personally -- he's also served on the State's Health Care Administration Board.

And we have benefited over the years, Joe, from your excellent advice. And I thank you for taking the time to be here today. I know just how difficult it is for you to find time, so I'm grateful to you for coming. Thank you.

MR. RIORDAN: I thank you for that compliment, Commissioner.

ASSEMBLYWOMAN MURPHY: Come back and let us know how we do.

COMMISSIONER FISHMAN: Don't worry, he will.

ASSEMBLYWOMAN MURPHY: The next person to testify is Gloria Alston.

Gloria, good morning -- good afternoon.

GLORIA ALSTON: Good afternoon. I thank the panel for allowing me to come today and speak as a caregiver. I'm a very emotional person, so please forgive me.

UNIDENTIFIED SPEAKER FROM AUDIENCE: I think you turned the microphone off.

MS. ALSTON: I was speaking in the microphone.

ASSEMBLYWOMAN MURPHY: You have to speak a little louder, Gloria, if you can.

MS. ALSTON: I talk to you as the caregiver of a mother that when you look at her, you really see just, maybe she walks with a cane. You think that maybe she just has leg problems. But my mom has Alzheimer's, and it's very difficult for me because my mother doesn't know who I am. I've been caring for her for many, many years. She's lived in my home with my husband and my children. I work full-time as a social worker with the Division of Youth and Family Services. I have a very stressful job.

Having a parent with Alzheimer's is also very stressful. I thank the Alzheimer's Association because, when she was diagnosed four and a half years ago, I didn't know what I was going to do. I'm the youngest of three. My brothers are in denial. They don't want to deal with it because it hurts them to see their mother that way. Well, it hurts me, too.

My mother has worked very hard to raise us. She's had a difficult life. Dale is so articulate, and I try not to get my emotions in, but I am an emotional person because I am under a lot of stress as a caregiver.

Not only do I thank the Alzheimer's Association for always sending information, I have my mother on the Return Home Program -- Safe Return Home Program. And thank God, because last year, Christmas, I had been up all night, and I worked the day before. I went and laid down because I had the flu. She left the house. My Christmas was shot.

It took us -- I called the Alzheimer's Association, the Return Home Program, and she was found in a few hours. I thank the Trenton Police. I'm from Trenton. I'm from Mercer County. And I felt -- I haven't had much time to Christmas shop, but I thought this was more important to come down and make an emotional plea for caregivers with young children, work full-time, and

take care of disabled parents because, as Dale said, a lot of us don't want to abandon our parents. And we feel it's an abandonment because, as my mother says -- even though she doesn't know me, I'm that lady that takes care of her -- "Please don't put me in a nursing home. I'll just die there."

Oh my God. That would stab at anybody's heart. But I feel stressed. It took me over a year and a half to get on the Respite Program -- the Mercer County Respite Program. I found out about that by chance.

My husband and I wanted to go away for two days. I was calling nursing homes. The price was \$250 to \$300 a day. I can't afford that. My mother didn't work until I was 14 years old. My father left her. Her income is minimal.

I work. I have a child at college. I have two at home. I work full-time. I can't afford \$250 to have a day of rest. And thank God for coming up on -- to the Respite Program. I just got on it in August. I get a grant of \$3000 a year to help with that, and I thank God that it's there.

But if I wanted to go away with my kids for a week, that's one-third of the grant. I feel stress. I'm getting a new job. I put aside my career ladder to take care of not only my mother, but my children. But I'm not a young woman. I'm near 50. So I took a promotion, but I'm in stress right now because I'm going to be traveling. My mother's day care center is from 7:00 to 5:00. No matter how hard I try to get her there so I can get to work at 9:00 -- my mother has lost the ability sometimes to remember how to go to the bathroom, where I'm cleaning up her room and the bathroom and getting my kids off to school. I'm stressed by 9:00. My job is that -- "You have to be

here by 9:00.” I said, “I understand that.” My job is important. I get a lot of gratification from helping other families, but you know what, I need help, too.

You know, 5:00, I may have six kids -- I’m a foster care facilitator. Last Thursday, five minutes to five, I had to place six kids. The day care center closes at 5:00. My husband, he’s at his job. His phones are off at 4:30. I can’t get him. I’m stressed.

I placed the kids -- I thank God that the Mercer County Adult Day Care Center has sensitive workers that understand my plea. But caregivers, we have to work. Society, we have to work. Economically -- I have three kids, a husband, a mortgage, a child in college, and I’m taking care of my mother. We need help.

Anyway, please don’t stop these programs. If you could -- I can’t imagine -- you know, being a social worker, people think you know everything about social work and any atmosphere whatsoever. I know about children and young families. Geriatrics, medicine, no. I’m learning. It’s hard. It’s hard.

The doctors don’t know. My mother has had five doctors in the past year, HMOs. That’s what she has because she’s a retired state worker. The doctor said to me, some people deal with the stresses better than others. I said, “Well, thank you very much.”

You know, how insensitive. Our jobs are insensitive. I know it’s a business. You’re taking care of families. But jobs need to be more sensitive to parents, caregivers that are taking care of parents that because of their condition, they don’t remember how to go to the bathroom. They don’t know how to clean their room. They’re not on a time schedule. My mother doesn’t know night from day. She only remembers two people -- my mother is only

77 years old -- and I am not one of them, and I've been a caregiver to her for years.

It's stressful. And I just want the State to be cognizant that caregivers have an enormous amount of stress and issues, and we're trying to do the best we can, but we need help, you know.

ASSEMBLYWOMAN MURPHY: Gloria, thank you.

MS. ALSTON: I'm beating a dead -- you know, I'm beating my drum, but without these programs -- and I still don't know what's in my community. When she talked about the one-stop shopping, I said, "Is Mercer County in that?" She said, "No."

ASSEMBLYWOMAN MURPHY: Not yet.

MS. ALSTON: Not yet. Well--

ASSEMBLYWOMAN MURPHY: I know, and now is the need, not when it gets--

MS. ALSTON: Now is the need because I'm not the only one. I have many people on my job with the same stresses. But I felt that for Christmas, if you tell everybody, let's be more sensitive to seniors, let's help these people. They deserve it. They made this country the way it is, and we need to support them and not abandon them. And I think nursing care has grown a lot, but I don't want to put my mother away to keep my job and keep my family because she's all that -- I'm all that she has.

Thank you. (applause)

ASSEMBLYWOMAN MURPHY: Thank you very much.

COMMISSIONER FISHMAN: Madam Chairwoman and other members of the committee: Deputy Commissioner Reinhard and I have to

leave at this point. I apologize to those who have not yet testified, but if you provide your written testimony, as we've requested, we'll have an opportunity to look at it, even though we will not be here personally to hear you testify.

To those who have testified, I thank you so much for sharing your personal stories and also your thoughts about what kinds of policy we need in this state going forward. This is exactly the kind of information we were hoping to get when we scheduled this hearing here. And I thank you all for coming forward.

I hope that we will be able to produce a set of recommendations to the Governor and the Legislature in which you will see your recommendations and your thoughts reflected. That's our job, and we'll do our best to carry your message to the Governor and the other members of the Legislature.

Thanks very much.

ASSEMBLYWOMAN MURPHY: Thank you, Commissioner.

Thank you, Deputy Commissioner. (applause)

The next person to testify, Gary Langfelder. Gary Langfelder? (no response) He is not here.

Keith Lannon, caregiver.

Thank you, Keith. You have been so patient. Thank you.

K E I T H T. L A N N O N: What was I going to do, cut in front of anybody.

I would say good morning, Council, but now it's good afternoon.

My name is Keith Lannon. I live in Ocean County, New Jersey. I'm 33 years old. I'm the primary caregiver for two senior family members, my father, Steven Lannon, and his sister, my aunt Mary Lannon.

I received a notice about today's event from Anne Macaluso (phonetic spelling). She's the Director of the Community Adult Medical Day Care. Without this information, I would not be here today to give you my testimony. Peg Nelson received my response very late yesterday afternoon. She had already completed her paperwork by the time I called, yet she took the time to record my name and give directions.

Thanks, Peg, whoever you are.

ASSEMBLYWOMAN MURPHY: She's right over there by that door, and she's my legislative aide, and she is very special.

MR. LANNON: All righty.

I would like to thank Governor Whitman for creating the New Jersey Advisory Council on Elder Care. I would like to thank the Council for being here to listen to the concerns and issues of New Jersey caregivers. I hope my testimony provides you with the insight needed to investigate and resolve caregiving matters.

I would like to acknowledge the GEMS Program in Ocean County, specifically Dr. Bryman and his entire team. This includes Dale, whose name I didn't even bother spelling or trying to pronounce. (laughter) They have been most helpful in all aspects of patient care as well as caregiving information.

I would also like to thank the entire staff of the Community Adult Medical Day Care for their excellence in caregiving outside the home.

It is my understanding that my testimony will provide you with the information you need to address caregiving issues. If I had all day, perhaps I could identify about 10 percent of all caregiving issues. Instead, I have about five minutes. The most significant point I can make is that I need information. I need anything I can get my hands on to educate myself and others. Getting my hands on it is the problem. You see, my hands are full: full of breakfast, lunch, and dinner; full of doctor's appointments; full of transportation to day care; full of laundry; full of unexpected accidents; full of all responsibilities for two other people and myself.

Perhaps I could let you know that I am a primary caregiver. I could officially register myself to the list of New Jersey caregivers, and you, in turn, could provide me with the information I need.

Is financial aid available? What veteran benefits apply to my father's specific situation? Are volunteers available for legal and financial planning? Are there special tax laws or exemptions for people in our situation? What happens when my COBRA health insurance expires? Is there a group policy health plan for those not working because they are caregiving? What help is out there? What help really isn't help at all, but rather money-making schemes targeted at the elderly?

If this information was sent to me, I would better know what to do and what not to do.

I would love to look it all up on the Internet, but my attention is occupied with taking care of my family.

Information is the only request I can make of you, but unfortunately, I can't be specific. Perhaps you could be specific and forward all information to all caregivers concerning the numerous needs we have.

Thanks for listening, and I hope my testimony has contributed to this worthy cause.

ASSEMBLYWOMAN MURPHY: New Jersey EASE, in Ocean? Yes, I think so.

Yes, there's another brochure for you. New Jersey EASE is the clearinghouse of the information -- the information and referral and a clearinghouse for one-stop shopping. I'll give you a brochure -- and we talked about that at 8:00 this morning, that we need to bring more of those to these meetings--

MR. LANNON: Thank you.

ASSEMBLYWOMAN MURPHY: --in the counties in which that service presently exists. But it is a place to begin for the myriad of issues and questions.

Thank you. (applause)

MR. LANNON: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. ROBINSON: There is a supply of these brochures in the back.

ASSEMBLYWOMAN MURPHY: In the back? In the rack? (affirmative response) In the back, in the rack, there is a supply of the New Jersey EASE brochures. Right there, where that gentleman is. So help yourself

and see if that doesn't begin to give you the key to starting the information search.

Carol Mazic, caregiver Is Carol here? (no response) Okay.

Dale Gordon, caregiver. (no response)

Val Straub Sr. Val? Val Straub?

VAL STRAUB: (speaking from audience) I only have two questions -- two statements.

ASSEMBLYWOMAN MURPHY: Okay.

MR. STRAUB: (speaking from audience) I've been a caregiver with my bedridden wife for 10 years due to neurological surgery for a meningioma, and the thing that--

UNIDENTIFIED SPEAKER FROM AUDIENCE: Go up there.

MR. STRAUB: (speaking from audience) I think they can hear me.

ASSEMBLYWOMAN MURPHY: It's to get your voice recorded, Mr. Straub.

MR. STRAUB: Oh, okay.

UNIDENTIFIED SPEAKER FROM AUDIENCE: It's intimidating.

ASSEMBLYWOMAN MURPHY: Oh, we won't intimidate you. We need to be sure we can hear it again.

MR. STRAUB: I'm in the recording business myself. I understand how it goes.

ASSEMBLYWOMAN MURPHY: Thank you.

MR. STRAUB: When I found out about this, I was considerably interested in -- there's a program that I am able to get a free health aide for two hours a day through our local family and children's service deal, which is terrific. And they told me about this, and so I was very glad to come.

The only thoughts I have, not really questions-- The time when you really need help is late evening, when you are pooped and your caregivee is also pooped, and it's very difficult to maintain the proper decorum that you've been able to do all day because you're just tired from taking care all day long.

I have -- I am able to afford, on a teacher's pension and Social Security, a health aide that I picked up privately, for five hours a day. That's all I can afford. Who takes care of the other 23, 20 -- what is it 20 hours, 19 hours? Okay. (laughter)

My math is lousy now.

ASSEMBLYWOMAN MURPHY: Some days just seem longer than others.

MR. STRAUB: Well, I never was very good in math. I taught basic electronics in school, and can you imagine, my youth -- well, that's another story.

So the point is, who takes care of her the rest of the day? Me, and it's rough at times. But after what I heard here, man, we're on a gravy train, I'm telling you. Because my wife has all her faculties. She's currently bedridden, but I can get her up in a wheelchair to go out and have dinner once or twice a week in the dinning room, in our home. And I have to get her on a SCAT bus, because she can only go -- she's wheelchair bound to go outside,

and I can -- I have to arrange for a SCAT bus to take her to the dentist, doctor, and so on.

And nobody makes house calls anymore. I can't understand that. So I asked a few of the doctors, and they said, "Well, it's because people won't pay for them. The customer won't pay, so we don't want to do it." That sounds strange to me.

Anyway, the prime deal is that if somebody had some kind of service to take care of putting your subject to bed, that's when it gets me. And bed hours are -- oh, I'm telling you, sometimes we get two, three, four o'clock in the morning. And that seems strange, but then we sleep all morning and are awake most of the night. That's -- our lifestyle has changed due to -- well, primarily how she feels about it and how I feel about it. We kind of work together on the thing, I guess.

That's about all I had. I think it's-- I say, after hearing all these -- I know Alzheimer's is one terrible deal, and I thank the Lord that my wife has all her faculties and we can live in the memories of our time. We met on a blind date in Japan, and we were both over there working for the government. We went together for a year and came home. And we are celebrating our 50th year next year.

ASSEMBLYWOMAN MURPHY: Congratulations, Mr. Straub.

MR. STRAUB: Thank you. (applause)

ASSEMBLYWOMAN MURPHY: Thank you for being here. And we do appreciate your speaking to us.

Dorothy Bukowski, caregiver.

DOROTHY BUKOWSKI: Do I have the right glasses on? Oh, okay.

Hi. Thank you for allowing me to speak. I just want to tell you that the way I found out about this meeting was my cousin, who lives in Reno, Nevada, found you guys on the Internet. And it said Neptune, but it never said where or what time. So because I work full-time and can't use the phone, I didn't find out about how to get here until Friday. But she must have called Carol Murphy's office, and whoever faxed all the information, including a map--

ASSEMBLYWOMAN MURPHY: Peggy Nelson.

MS. BUKOWSKI: Peggy Nelson, she was wonderful.

ASSEMBLYWOMAN MURPHY: Yes, she is. (applause)

MS. BUKOWSKI: Yes, she was.

So while I wrote this testimonial last night, by hand, faxed it to June in Nevada, She typed it, and she called me at 6:30 in the morning, saying, is it okay? And so this is her typing.

ASSEMBLYWOMAN MURPHY: An electronic age, isn't it?

MS. BUKOWSKI: Oh, I'm telling you, my fastest finger is my fax finger.

I'm going to be talking about a couple of members of my family. My mom was in my care longer than I was in hers. When my dad died, I was young, and became head of the house. It was difficult trying to please mom by being her child and the adult who works and provides financially. I had to work long hours and had no car, and by the time I got home, she would have

turned off the furnace, the hot water, the telephone and the refrigerator, and cry that she was lonely.

I had to lock my door to sleep, and couldn't stay in the bathroom at all because she would be at the door, complaining she had to go. Because of all of this, I had to move from a house to an apartment, so she wouldn't feel free to take the house apart.

She had such strong control in her family that although she reacted well to strangers, she only wanted to be with family, because she wanted to be herself, which was controlling and sometimes nasty.

I myself could never afford to have her be in her own place that she would be happy with. No funds were available to me unless I abandoned her in the street.

I have a brother who is 17 years my senior who lived in New York state, with his wife. My brother was not required to reciprocate with New Jersey because it was outside of their jurisdiction. I couldn't take action against my brother to provide for the support of my mother without my mother's consent. Even food stamps were not available, because my mom refused to sign for them.

Also, when she died in the hospital, the hospital hounded me until I paid the bills, even though she had not worked for the last 70 years of her life.

To pay the hospital bill, I took a second job taking care of an 82-year-old senile lady. I was very good at that because I knew how to take care of my mom very well. I stayed at this woman's house at night, five days a week. I had a cleaning woman come in twice a week and a nurse that came in

on Saturdays to check up on her, groom her, and take her to the beauty parlor and the doctor's office. I also took care of her cat and hired people to take care of the inside and the outside of the house.

After a year I left because I had made enough money to pay the bills, and she is now still alive living in her house. But I don't know if she is okay because you don't know who you're hiring these days.

Now, another relative I would like to tell you about is Uncle Leo, who died in Linden in October 1997. Leo was married to Aunt Isabel who was ill most of her 78 years. Isabel's side of the family loved her so that one by one, as they died, they gifted her with all their worldly possessions.

So Isabel and Leo, in their old age, hired a cleaning lady named Grace a few hours a week. Leo took care of Isabel and worked, and later retired, but still raised canaries. When Isabel died, he was fine, but soon after, his brothers started to die, one by one. He realized he was truly alone and became ill. At this time, Grace the cleaning lady accompanied Leo to his attorney's office, where Leo was encouraged to change his will and gift to Grace, his cleaning lady, all he and his wife worked for and which was supposed to go to his remaining family members, along with all the money and property he and his wife had inherited.

Leo became mysteriously sick and died, and during the last few weeks, we, his family members, were denied visitation rights to our Uncle Leo by Leo's cleaning woman Grace and his attorney. We believe that our dear uncle may have been involved in an assisted suicide.

When we realized something was suspicious, we automatically filed caveats protesting the probate of his will. We were correct. Five members of

Leo's family filed caveats. I was the first. And Union County Surrogate, Ann Conti, came out of her office and was upset and questioned me if I had ever done this before.

The cleaning lady and the attorney who drew up the new will tried to probate the will the day of our uncle's funeral. The Union County Surrogate's Office refused to seal off the house, and the Union County Prosecutor's Office refused to investigate this. And the Linden Police Department refused to seal off the house at 811 Summit Street, Linden, as done previously in another family estate matter and as required by their General Order, which is part of their standard operating procedures.

Surrogate Ann Conti is President-elect of the National College of Probate Judges and coauthored the book on national probate court standards on handling estates and guardianships. Conti also coauthored several training manuals and belongs to several fiduciary relationships and worked -- and several committees and attended conferences on elder abuse, guardianships, fiduciary relationships, and worked with several Union County judges, for example, Assignment Judge Edward Beglin, Judge John Boyle, and Judge Frederick Kentz, on guardianship and elder abuse manuals, including persons who are too sick to take care of themselves.

When we, the family, filed counter-complaints to an order to show cause to probate the new will, Judge Beglin immediately changed the venue and moved the case to another county, without notice to us and without giving us a reason or an explanation for doing so. This is the second time in 10 years that Surrogate Conti has refused to protect the elderly and the assets of an estate in the same family.

June Wisniewski, my cousin, who I mentioned before, lives in Nevada, and a caveator of Leo's estate, will be sending you testimony of further abuse, corruption, collusion, and conspiracy from her father's estate in Union County. June was never allowed to see her father's body, the will, and most of the assets in an estate worth over \$700,000. And the Linden police seized and sealed off the estate house in June's father's case but refused to do so in her uncle's case.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you for coming today to speak for your cousin June. We appreciate it. And thank you for your patience in sitting, Dorothy.

MS. BUKOWSKI: If anybody wants to talk to me afterwards -- if anybody has anything similar, I'd be happy to talk to them.

ASSEMBLYWOMAN MURPHY: Did you leave testimony with the--

MS. BUKOWSKI: I will -- I left it with the lady in the front.

ASSEMBLYWOMAN MURPHY: Oh, thank you. Okay, that's fine. Thank you very much, Dorothy.

MS. BUKOWSKI: Thank you. (applause)

ASSEMBLYWOMAN MURPHY: Joan Cowitz. Joan Cowitz?
(no response)

And the last person on our list today, Anna McCall. Anna McCall?

A N N A D. M c C A L L: Good afternoon, or is it still morning?

ASSEMBLYWOMAN MURPHY: Good afternoon, Anna. It's afternoon. Thank you, Anna.

MS. McCALL: Yes. I'm not too well prepared to be here, but I hope that you will just bear with me for a few moments. I'm 83 years old. I have lived in Neptune Township for 56 years. I'm originally from upstate New York, and my husband from Ohio. We met during the war, had a few dates, and got married, and we've been putting up with each other ever since.

What I'd like to -- what has occurred to me-- I only heard about this gathering as of yesterday, and I'm suffering an ear -- putting up with an ear infection, but I wanted to be here to hear what was going on throughout the state.

I can't say enough for the need for assistance of every kind for Alzheimer's patients and families. We -- both, in my -- particularly in my husband's family, there are cases, and we understand the need, and some of our friends, also. There is no greater, no sadder way for a person to go. And the grief and the sorrow on the family is unspeakable.

That's all I'm going to say on that. I just want you to know that I feel very compassionate about this entire situation, and whatever the State can do to help this situation, I would be very grateful for all others.

I would like to mention the fact that -- and I don't want to sound as if I don't care -- but my parents, both of them, came from Sicily. We don't belong to the mafia. (laughter) But they were Italian-speaking people, of course. And my father had to come first and send for my mother later.

We were brought up speaking the Sicilian dialect, but now and then my father would bring in the Roman Italian -- proper Italian. However, for some reason--

Oh, I must tell you this. My mother died when we were all very little. I was second to the youngest. There were five children, and I was seven years old. And my father brought us up. He later remarried, in Italy, again. His sister found somebody for him.

But the thing I would like to bring out is that my father and mother, while she was alive, though we spoke Italian at home, were very anxious for us to learn the English language so that we could teach them. And they, in turn, would be better aware. We never felt that there had to be any special attention given to the fact that we were Italian-speaking people. We managed very nicely, and I remember helping my father read and study to acquire his citizenship here in the United States of America. He was very proud to be accepted as a United States citizen. He knelt and kissed the ground and the flag. He loved his country very much, but he was -- he considered himself an American after his citizenship.

I just would like to say that I feel, sadly, that there is a lack today and has been for some time of family structure. Children are being born, and grandparents are taking over, sadly. Where are the men who fathered these children? It takes two people to father a child. There is not enough -- this is a strain on the grandparents.

Have I said something wrong? (referring to sound of fire alarm)
(laughter)

ASSEMBLYWOMAN MURPHY: No, I think that's the fire alarm for the town.

MS. McCALL: Oh. Pardon me.

ASSEMBLYWOMAN MURPHY: I wondered, too.

MS. McCALL: That's all right. I didn't want to offend anyone, but I think that while we -- while anything that can be done to help seniors, certainly I am for; although, I can remember living behind the shop -- a little shoe repair shop, as a child. And I remember my mother knitting doilies to put over orange crates to make things look a little better. So I know whereof I speak as far as growing up in a household where there were -- the finances were extremely low, but there was a great deal of love and proper training, from the standpoint that we were taught not to hate anyone. Anyone was welcome in our home, as I recall, regardless of religion or race, as long as they behaved themselves.

My father taught us to not entertain any form of hatred, which I think has maligned our nation and caused a great deal of-- Babies weren't born hating. Someone incites them. Unfortunately, some of these people are older people, on all sides. I'm not picking on anyone.

But I just want to say that I thank you for listening to me. I hope you understand where I'm coming from, but I feel the lack of family structure, in itself, where even the younger help to take care of their parents. I'm not speaking of Alzheimer's now. That's a different subject. But in a loving caring way.

And I want to thank you all for allowing me to speak. And excuse my appearance. I wasn't really dressed--

ASSEMBLYWOMAN MURPHY: We're delighted that you came and that you did choose this opportunity to speak to us, Ms. McCall. Thank you so very much. (applause)

Ladies and gentlemen: we have gone through the list of people who had asked to testify today.

We thank you very much for being with us, and we thank you for coming down here and making this a very interesting--

Yes, ma'am?

MS. STRACK: (speaking from audience) Is there anyone who needed these brochures? They're hand done, but we have--

ASSEMBLYWOMAN MURPHY: Okay, there are extra New Jersey EASE brochures. Please take one with you and find out what the service is about, as I say, not available in every county. In 13 now, and it will be available in the entire state within the next year, I firmly believe.

Thank you again, ladies and gentlemen. Tremendous for the Council. You're marvelous people. Thanks.

(HEARING CONCLUDED)