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# ***Council Meeting***

of

## NEW JERSEY ADVISORY COUNCIL ON ELDER CARE

*“Expert presentations on caregivers and caregiving of the elderly”*

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**LOCATION:** Room 319  
State House  
Trenton, New Jersey

**DATE:** November 13, 1998  
9:00 a.m.

### **MEMBERS OF COUNCIL PRESENT:**

Assemblywoman Carol J. Murphy, Chair  
Senator Robert W. Singer  
Senator Norman M. Robertson  
Assemblyman Samuel D. Thompson  
Assemblyman Louis A. Romano  
Len Fishman  
Susan C. Reinhard  
Ruth M. Reader  
Theresa L. Edelstein  
Renee W. Michelsen  
Roberto Muniz  
Joanne P. Robinson



### **ALSO PRESENT:**

Irene M. McCarthy  
*Office of Legislative Services*  
*Council Aide*

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

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**ASSEMBLYWOMAN CAROL J. MURPHY (Chair):** Ladies and gentlemen: I'm going to ask you all to join us as we begin the second meeting of the New Jersey Advisory Council on Elder Care. We will be passing out to the members who are sitting up here the corrected membership list of the Advisory Council, with phone numbers and fax numbers and whatnot that were given to us at the last meeting, with a summation of the events that took place at the last meeting, commentaries, etc., for your review. Please address questions or discussion to myself. And the dates for meetings and public hearings -- please note that the public hearing that is scheduled for December 9 -- the time was changed on that.

I believe it was Senator Singer and Assemblyman Romano noted that leaving Newark at 4:00 we could be just one more traffic problem, and we certainly don't need to add to anyone's congestion on the highway. So we will begin that meeting at 12:00, and we will be out of there at 3:00 p.m. So those things are established, and I believe you have a copy of today's agenda in one of the folders in front of you.

I am going to simply say that I am very excited about this Advisory Council. I am very interested in the presentation of these wonderful experts who have taken their time to come to us today at the beginning of our education process. As you will note, they are speaking in time frames that are pretty tight, so I would ask you all to try and pay attention. Questions can be addressed, obviously, as we move along.

And Vivian Greenberg will not be able to be with us today, but she has given to each of us a copy of her book, *Respecting Your Limits When Caring for Aging Parents*. These are all parts of the material that we commend to

everybody for their review in their reading as we move through this Council and its deliberations.

I'm going to ask for a roll call, Commissioner, and then we will move to you for comments, if you please.

I'm saying, "Ask for a roll call." I think I'll do it myself since I'm here.

Theresa, you were not here last time. Perhaps you would like to say good morning.

MS. EDELSTEIN: I'd be happy to. I'm Theresa Edelstein. I am the Director of Continuing Care at the New Jersey Hospital Association. I have been in that capacity for just over a year, and I'm also a licensed nursing home administrator in New York and New Jersey.

ASSEMBLYWOMAN MURPHY: Thank you very much, Theresa. Bernice Shepard is not here at this time.

Renee.

MS. MICHELSEN: Good morning. I'm Renee Michelsen. I represent Atlantic Health System. That's Morristown Memorial, Mountainside, Overlook, and Passaic General Hospital.

ASSEMBLYWOMAN MURPHY: Thank you, Renee.

And to your right, Roberto.

MR. MUNIZ: Good morning. I'm Roberto Muniz. I'm the President for the Francis E. Parker Memorial Homes in Piscataway and in New Brunswick. I am also a member of the Commission on Aging for the State of New Jersey, and I'm really excited about being part of this great committee (*sic*).

ASSEMBLYWOMAN MURPHY: Thank you.

Susan.

DEPUTY COMMISSIONER REINHARD: Susan Reinhard, Deputy Commissioner at the Department of Health and Senior Services.

ASSEMBLYWOMAN MURPHY: I will let you wait for a minute because you have more to say than just hello, and I want to hear it.

COMMISSIONER FISHMAN: Okay.

ASSEMBLYWOMAN MURPHY: Senator.

SENATOR SINGER: Good morning. Senator Bob Singer from Ocean, Monmouth, and Burlington County.

ASSEMBLYMAN ROMANO: Assemblyman Lou Romano. I cover northeast Hudson County.

ASSEMBLYMAN THOMPSON: Assemblyman Sam Thompson, portion of Middlesex and portion of Monmouth County.

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

ASSEMBLYWOMAN MURPHY: Thank you, Joanne.

DR. ROBINSON: Thank you.

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

ASSEMBLYWOMAN MURPHY: Thank you very much.

And now, Commissioner Fishman.

COMMISSIONER FISHMAN: Thank you very much, Assemblywoman Murphy.

It's great to be back here again today. Like the other members of this Council, I'm looking forward to hearing from some experts of national renown as we make our way through the agenda today.

I also want to acknowledge some of the folks that we work with on a regular basis at the Department starting with Dr. Tom Cavalieri, who is here this morning. He is the Chair of the Department's Commission on Aging.

Tom, it's nice to have you here. Glad you could make it.

I also want to acknowledge some folks who are here from the County Offices on Aging, which are really a vital part of the services that are provided to seniors in our state. Gloria Lane is here from Bergen County.

Gloria, nice to see you.

Marilu Gagnon is here from Atlantic County. Marilu, great to have you here.

And also Grace Egan (phonetic spelling) from NJ4A is with us this morning. Good morning, Grace.

Any other County Office on Aging folks who I've missed?

UNIDENTIFIED SPEAKER FROM AUDIENCE: (indiscernible)

COMMISSIONER FISHMAN: Great. Nice to have you here.

Thank you.

Well, we've got a very impressive group of nationally known speakers, and I'm delighted that we were able to assemble such a fine panel this morning. We're going to hear a lot about caregivers and caregiving from our panel of speakers. Before they begin, I want to lay out what our State has been doing in the area of elder care services.

Let me call to the attention of the members of the Council this blue folder (indicating) that has within it our ever-popular publication *Selecting a Long-Term Care Setting*, also, a little brochure that describes New Jersey EASE, and then the handouts that you see on the inside. There will be slides on the screen that correspond to your handouts. We're going to have to do some massage therapy for the people in the audience who will be looking over their shoulders, if they choose to, at the slides behind them.

Well, let me begin by providing a little context, and we're ready for the first slide. (begin slide presentation) In New Jersey today, there are about 1.4 million seniors. By the year 2020, that number will have grown to over 2.3 million. You can see from the chart on the left-hand side and the blue bars how dramatic the increase will be in the number of seniors. Even more dramatic will be the rate of growth among those who are 85 years of age and older.

Two years ago, Governor Whitman created the Department of Health and Senior Services so that New Jersey could focus more attention on the growing numbers of seniors in our state and also improve the coordination of services that are available to them and I think as well to spur innovation in programs for seniors. New Jersey is now only one of a very few states in the country with an agency that offers the full array of services for seniors, ranging from Older Americans Act Programs, which link us to the vital area offices on aging, to meals-on-wheels, our CHIME Program, the Pharmaceutical Assistance for the Aged and Disabled, or PAAD, Program, to the regulation of long-term care facilities, and responsibility for our State's large long-term care Medicaid budget.

When the Governor created this Department, she had four goals in mind. The first was obvious, which was to take 20 programs that were scattered over four different departments of government and put them together in one agency that could do a better job of promoting policy and coordinating these programs. So this is the first time in New Jersey's history that we have a department that is dedicated to the interests of seniors, and I'm proud to be the first commissioner of that department. I'm also very proud of the first Deputy Commissioner for Senior Services in our Department, Dr. Susan Reinhard, sitting to my right.

Working with her is Ruth Reader, an Assistant Commissioner at the Department, and Ruth is especially active in trying to bring about our second goal, which is to make it easier for seniors and their families to access the services and programs that we offer, to access them at the local level, and to help seniors live in their homes and communities as independently as possible. To do that, we created a program that we call New Jersey EASE. It's a telephone information and referral service. It's at the county level. EASE stands for Easy Access, Single Entry, but what it means simply is one-stop shopping for all services that seniors need.

This idea of one-stop shopping at the county level sounds very simple. Radical ideas often do, but I can tell you that this represents a real sea change in how we make services available to seniors. If you've ever had the experience of trying to learn about or assemble a package of services for a family member or a friend, a senior who needs them, you probably had the experience of having to call many agencies, getting asked the same questions over and over again, and perhaps most frustrating of all, not having anybody

who is prepared to take overall responsibility for helping to assemble a support system that a senior may need.

Well, the purpose of New Jersey EASE is to change that. By calling one New Jersey EASE number, seniors get a live person, not a recorded message, and this person has been trained to understand and convey to people who are calling all of the services and programs that are available and, if necessary, to refer the caller to the next level, which can actually help to navigate this system, put a system -- a package of services together, do an assessment, if that's necessary, and so on.

So that's our goal, to have a one-stop shopping system in every county in the state where seniors and their family members can get this kind of help, information about our home-delivered meals, about our PAAD Program, utility credits, transportation, property tax relief, or help with their insurance.

There are now eight counties that are in our New Jersey EASE Program. And if you look behind you, you can see those are the counties in yellow (indicating slide). Our ninth county, Sussex, is being added today, later this afternoon, and we expect all 21 counties to be on board by the end of next year. You can see those in purple will be the next wave of counties to come on, and then those that are in turquoise and white will be the last phase of counties to join.

A natural adjunct to this service would be to provide universal screening for people who are at risk of entering a nursing home. We do this now for people who may qualify for Medicaid within six months, but we'd like to extend this service to counsel all older adults about their options, including

home- and community-based care. This sounds easy to do. It's a little more complicated than that.

And, Madam Chairwoman, I hope that we will have an opportunity at this Council to discuss how we can implement a universal screening program. I think it's a very important step for us to take.

This touches on our third goal for our new department, which is to increase the number of long-term care options that are available to people who need them. All of us want to maintain our independence and dignity as we get older, and we all want to live in our own homes, if possible, and in our communities. Few, if any, of us would choose to go into a nursing home if we could remain in our own homes and communities. It's really that simple.

The next slide shows you the mix of services that we have to offer that is a comparison of home- and community-based services to nursing home services. And while we're waiting for the slide to come up, you can look in your handout. It's the one that says Nursing Home vs. Community-Based Care. And what this chart pretty dramatically demonstrates is that the vast majority of seniors who are receiving long-term care assistance from the State reside in nursing homes. The blue bar shows you the nursing home residents, and the red bar shows you the residents who are receiving State assistance to live in their homes or in their communities.

In fact, New Jersey spends more than 90 percent of its long-term care budget on nursing home care. And I should point out that it's clear that our State's appropriation for this portion of our budget will be increasing dramatically in the coming years. We simply cannot sustain a system that spends so much money on providing care to seniors in nursing homes. Even

if we could afford it, it would be the wrong thing to do because we need a system of services and options for seniors that is more balanced than the one that we have today.

So let me show you what a couple of other states are doing to try to repress the imbalance that we're working on here in New Jersey. The next chart that you have, which says Nursing Home vs. Home- and Community-Based Care 1995-1998 in Oregon, shows you what a system looks like when it's more balanced. If you put these two charts together, you can see that in Oregon the overwhelming majority of residents who receive assistance from the state are getting it in their own homes or in their own communities instead of in nursing homes. Oregon is regarded, I think, by most people perhaps universally as the national leader in this respect.

I should mention by the way that we've got an Oregon transplant here sitting in the audience, Leslie Hendrickson, who is Assistant Commissioner at the Department, who is responsible for making Oregon look like it does, as summarized by this chart, and who is helping us bring about a more balanced system here in the State of New Jersey.

The next chart shows you what another progressive state has accomplished, and that is the state of Washington. You can see that their balance is a little closer to an even mix between nursing home and home- and community-based services, but again Washington has been a pioneer in providing a much more balanced system of services and programs for seniors that allows them to stay in their own homes and in their communities.

The next handout shows you how New Jersey compares with other states in our ratio of nursing home beds to residents who are age 75 and over.

This chart may be a little tough to understand. Let me see if I can help you interpret it. Again we're looking at the ratio of nursing home beds to residents living in a state who are age 75 or over. So look at the thick, red line. That's the national average and you can see that-- The national average has been moving up a little bit from about 116 or so nursing home beds to every 1000 residents 75 years of age or over in 1994 to about 119 in 1996. The national average is going up.

You can see that there are a number of states that we've identified that are below the national average. The lowest by far is Oregon. That's the blue line at the bottom, where the ratio is about 70 beds to every 1000 residents age 75 and over. New Jersey is the pink line that is dropping, and our ratio, you can see, is around 100. We are well above Oregon, a little bit above Washington state, below our neighbors, New York and Pennsylvania, and below the national average.

Now, why is it that we're aspiring to be more like Oregon in this respect? The reason is that when you have a smaller number of nursing home beds to seniors age 75 and over, you have more room and more flexibility to add options that meet the diverse needs of seniors. And I'll talk about what some of those options are in a moment, but let me stop here to say emphatically that nursing homes will always be an essential part of the long-term care continuum. The fact that we want a more balanced system does not mean that we don't appreciate the role of nursing homes. In fact, I'm very proud of the quality in general of nursing homes in the State of New Jersey, and we want to help them be the best facilities that they can possibly be.

But it's also clear that not everybody needs the intensive care that a nursing home offers. For those seniors who do need nursing home care, my Department has been working together with nursing homes to improve the quality of care that they offer. Using a major grant from the Robert Wood Johnson Foundation, we are now monitoring on a continuous basis key quality-of-life indicators at participating nursing homes. This is the first project of its kind in the country and is representative of the kind of effort we're trying to undertake collaboratively with nursing homes to improve the quality of care there.

Older adults have clearly voiced their desire to stay in their homes and in their communities as they age, and it's our job to provide them with more of the options that they want. And that's been an important goal for us -- to encourage long-term care options like assisted living and alternative family care. If you're not familiar with these options, let me briefly explain them.

Let me start with assisted living, which marries apartment-style living with supportive services. I don't think we've got handouts for that, and if we don't have slides, I'll simply say that--

Oh, it looks like we've made it just in time. That's great. Let's go forward a few slides until you hit the one that shows an assisted-living facility. All right, okay.

I appreciate your heroic efforts here (speaking to slide operator), but let me see if I can describe in words what a picture is very useful in conveying.

Assisted living is really an attempt to provide a more residential kind of care for people who are nevertheless quite frail. For those of you

who've seen the better examples of assisted living, there is a very distinctive residential ambience in architecture. Every resident in an assisted-living facility has his or her private apartment. There are kitchen facilities within the apartment to emphasize that residents are in their own home. There's a private bath. Residents can lock their own doors, which again emphasizes the privacy -- the fact that one is living in their own place. Assisted-living residents can do some modest cooking on their own. Of course, they also have congregate meals offered to them. The idea is to assist them with the activities of daily living but not to provide the intensive level of care that a nursing home provides.

The challenge in New Jersey, as elsewhere, is to make assisted living affordable. And I'm pleased to say that New Jersey has obtained a waiver from the Federal government that allows us to use Medicaid dollars for people who qualify so that we can offer assisted living to them if they're not able to pay at the private rate.

Alternate family care, or adult foster care, is when a frail elderly person comes to live in the home of a trained caregiver. In alternate family care, a caregiver provides a room, meals, personal care, and other supportive services to somebody who would otherwise probably need to go to a nursing home if that other option were not available to them.

If you look at the next slide, you can see that in 1994 there were only two alternate family care agencies in New Jersey, represented by the two green dots. There were no assisted-living facilities in New Jersey back in 1994. Compare that with the next handout. The yellow dots show you the 49 assisted-living facilities. Actually, there are another 21 facilities we call

comprehensive personal care, which means that altogether we have 70 assisted-living facilities in New Jersey today, and we have 13 alternate family care agencies that are providing care in alternate family care programs.

We would like the alternate family care program to grow even more than it has, and one of the major impediments right now is our State's boarding home law. I know that Senator Singer is well familiar with this and is poised to introduce legislation that will change that. In order for alternate family care to really reach its potential, we have to amend the boarding home law. And I hope that this is the session in which that will happen so that more and more people can get the advantage of this option. Perhaps this Council can provide some impetus to that effort.

One of our more popular home- and community-based programs is the Community Care Program for the elderly and disabled. And last year, Governor Whitman authorized a 10 percent increase in this Program. This is the first expansion in many years and will allow us to provide for care to 3300 people in our state. Our Respite Care Program, offering caregivers a needed break, has helped thousands of people since it began 10 years ago. And last year, the Governor and the Legislature authorized another million dollars for this Program. This is the first expansion in its history, and it is certainly welcome because many people are eager to use it who have not been able to get the benefits of it in the past.

The Governor and the Legislature also authorized an additional three-quarters of a million dollars to expand our Adult Day Care Program for people with Alzheimer's disease. I know that Dr. Steve Zarit, who is in the

audience now, will be testifying on the success of this Program in reducing family caregivers' burden and depression.

Both our Respite Care Program and our Adult Day Care Program are national models. And included in your handout is testimony that Dr. Reinhard provided to the United States Senate Special Committee on Aging. Her testimony explains these Programs further.

Well, as I've tried to indicate, we're trying to create a continuum of services that reflects the diversity of the needs of the seniors who live in our state -- from people who can live independently and simply need some help with pharmaceuticals to those who are more frail and need assistance through assisted living, alternate family care, or a nursing home.

What I've been talking about so far are the formal long-term care options that we offer in this state, and we've been laying the foundation for more of them. And I think that the next five years will perhaps be the most exciting time in long-term care in our state's history. But even more important is the informal system of long-term care that goes on every day in our state, and that is families taking care of family members, friends taking care of friends. And this informal system includes probably many of the people in this room. Nearly one in four American households has somebody caring for a relative or a friend who is ill or impaired. That's 22 million people.

We know that these caregivers are jugglers. They juggle families, jobs, and personal lives. The average caregiver provides at least 18 hours of care per week, while one in five provides about 40 hours of care a week. Again this is the informal caregiving network. Many give up work to perform this important work. Others report physical or mental problems as a result. And

I think we all know that because our society is so much more mobile now, many kids are trying to help manage their parents' care at long distance. It's a very difficult challenge.

Some of the things that I've already mentioned we hope will help what has become to be known as the sandwich generation, the generation caring for their own children and at the same time trying to provide assistance to their parents. The PAAD Program, the Respite Care Program, meals-on-wheels -- all of these things can help. Equally important is New Jersey EASE, which increasingly will be used by seniors and their families to put together a system of support that seniors need. One of the things that I hope and I expect that this Council will be talking about is how to support the efforts of this informal caregiving network, which is so critical.

This brings me to our next to last slide, which is the one that is comprised of a series of concentric circles, and this slide really captures the philosophy of our Department of Health and Senior Services. The outer circle, this turquoise circle, is the one that we call wellness. It's comprised of things like seniors getting good diet, exercise, social stimulus at places like senior centers, and of course, prevention. Prevention means things like getting the pneumococcal and the influenza vaccine -- a major campaign that our Department has undertaken this year and last. It also includes things like Healthy Bones, a program that's intended to avoid the ravages of osteoporosis, and health screenings, which we hope to expand particularly in communities of color. The yellow circle represents home and community services. Things like home care and home-delivered meals. The next circle represents things like alternate family care, assisted living, residential health care, settings for

seniors who can no longer live independently but do not need a more intensive level of care. And then, finally, that red circle at the center represents nursing home care for the most frail elderly who require that intense level of care.

If I were to tell you very simply what our Department's trying to do for seniors in our state, it would be this. We're trying to help them stay on these outer circles where the quality of life is highest and where they can live most independently and with the greatest dignity. That's really what we're all about, and I think that's what most of the senior advocates are about as well.

This final chart lists the four items that AARP's National Public Policy Institute identified as the things that the most progressive states in the country were trying to do. Those four things were to consolidate state agency administration, develop single points of entry at the local level, expand home- and community-based services, and then encourage more residential settings.

Several of the states around the country are doing one of these things. A few states are doing two or more. I'm very proud of the fact that New Jersey is doing all of these things. We've consolidated services for seniors in one department, the new Department of Health and Senior Services. We're building New Jersey EASE at the county level. We've expanded residential home- and community-based options with assisted living, alternate family care, and by expanding CCPED. We are certainly trying to create more residential settings for seniors. We're laying the infrastructure, but we know that there is a lot more to do.

This concentric circle that we looked at a moment ago is really the vision that we're trying to promote for serving seniors and helping their families help seniors as well. Today is one of those rare opportunities to absorb

the insights of experts from around the nation. I know that the information that we receive today will help us build an even, more balanced system. One that really reflects the diversity and the diverse needs of our seniors. (end slide presentation)

Madam Chairwoman and Council members: I'm glad to have had this opportunity to share with you some of the things that our Department is doing. I'd be happy to take any questions if you'd like or yield to the next speaker.

Thanks very much.

ASSEMBLYWOMAN MURPHY: Thank you very much, as always, Commissioner. We know that you are working for the betterment of all of us.

Sam.

ASSEMBLYMAN THOMPSON: Madam Chair, first I would like to cite a statistic I heard last night that adds another perspective to the challenge that we're facing. On *48 Hours*, they mentioned that currently there are 10,000 people that are 100 years old or older. By the year 2040, they said this number is anticipated to grow to 1.4 million. Not only that we'll be dealing with more seniors, but seniors who have a lot more years to live.

SENATOR SINGER: By the way, Lou claims to be-- He'll be the oldest legislator who's going to be here. (laughter)

ASSEMBLYMAN THOMPSON: Commissioner, you gave the figures comparing the number of individuals in nursing homes versus home- and community-based care for Jersey and other states. Now, I would-- I think you indicated, and I would tend to agree, that probably those in the home- and

community-based care as a population tends to be less frail or healthier than those in the nursing home. But if you can compare an individual who is relatively healthy in a home-based setting versus a nursing home, what would be the ratio of the cost -- nursing home versus at home? Any idea?

COMMISSIONER FISHMAN: Well, it depends. I think what you've laid out is exactly the right framework. If you think about senior services, you need to think about a continuum that ranges all the way from somebody who is living independently and maybe just needs a little assistance with transportation -- that's actually a very important issue, I'm sure we'll be hearing that over and over again -- all the way to a senior who can no longer live independently and needs the intensive services that a nursing home provides.

Our goal is to create a system that has so many options that a senior can get plugged into the options that are right for them. It is true that the frailest seniors are those living in nursing homes. It's also true that there are many very frail seniors who can live in a less-intensive setting, like assisted living, like alternate family care, or who may even be able to stay at home with family members if those family members had more support. And one of the things that our State needs to figure out how to do is to offer support for families that are undertaking the care of a very frail senior.

To give you just some benchmark, Assemblyman, the average nursing home costs the State for a senior who is a Medicaid beneficiary a little over a \$100 a day. Someone who is in an assisted-living program is probably, if that person is a Medicaid beneficiary, incurring costs of roughly \$60 a day. And someone who is living in an alternate family care setting is incurring costs

of roughly \$40 a day. So if we can make sure that seniors are using the option most appropriate for them, not only will they enjoy a higher quality of life, but it also makes the most sense in the terms of the State's financial outlays.

In states like Oregon and Washington, which have really been national pioneers -- will tell you not only that their seniors are happier and not only that their seniors -- actually that they are serving more seniors in other states, but that they have enjoyed a commensurate savings because they've been able to plug seniors into the level of care if they need it that's most appropriate.

ASSEMBLYMAN THOMPSON: You got to the point that I was looking for there, and that is that for the same dollar, not that we could be saving money, but rather that for the same dollar we can assist more seniors. And they may well end up with a better quality of life, too, if we can keep them in the community- or home-based setting.

COMMISSIONER FISHMAN: I agree.

SENATOR SINGER: Madam Chair, may I just--

ASSEMBLYWOMAN MURPHY: Yes, Senator.

SENATOR SINGER: --and I don't want to delay the meeting, but I just must say something, Commissioner, in due deference. And I know we appreciate-- We always use the philosophy of Oregon and Washington because-- And they're a different animal than we are. If you take a look at my particular region of the state, if the state was on a plane, it would be tilting in our direction. I don't think many people realize the magnitude of how we're growing. A senior developer opened up a senior community last year -- 1000 units of seniors. He's already half sold out. Another developer just finished

1700 units of seniors. The majority of these seniors never lived in this area. They come from out of state and they come from-- There is not support group. And, true, they're not poor people, but they're moving into our state at a tremendously rapid rate.

There are some problems we have to also understand the State has forgotten about. Assisted living is a wonderful alternative. We never put enough money in the pot to make the jump from nursing home to assisted living. There's like a period of time where you have to overlap with nursing home and assisted living. There just isn't enough money. We didn't put enough money in your budget to do some of that. We're going to have to look at that very, very carefully because that's important. You're going to have a double cost for a while until you make that jump.

And, second of all, you have to look at assisted living because many nursing homes have taken a group of rooms and say, "That's assisted living," and they change a little decor. It's really not. It's a kind of a facade-looking thing but truly not assisted living.

But one of the major problems we find -- and it's really twofold, and one you touched on is transportation. In our area of the state, it's critical because every senior has to go to a doctor and every senior has to go out, and there is no transportation to speak of. But secondly is, as Secretary-Treasurer of the County Board of Health, we run the largest visiting homemakers service and nurse service in the State of New Jersey. You cannot get people to work for the wages that visiting homemakers pay. You get it in bad times when everybody is unemployed, but in good times you can't get it. And the truth of the matter is, if we don't change that whole system of how they're going to be

reimbursed back and how we're going to pay those people, you're never going to have the caregivers available no matter what you want to do to provide that service. And that's a very interestingly fact if you think about it.

If a person can only make \$250 or \$300 a week or \$350 a week as an aide, how do they live? They don't. And therefore you're really limiting who can get those kind of jobs. And the more things we put on with background checks, which are necessities, again the less people are getting involved in that whole thing. So though the -- certainly the purpose is wonderful. If we want to do that, we've got to take a look at some point of how that whole system is all about -- the fact that they're not paid benefits, the fact that they're not paid enough, and where are we going to get those caregivers and what we're going to do for those caregivers to be -- even if you have the money -- able to find those people and work with those people. It's a very, very important issue for us.

COMMISSIONER FISHMAN: I think all of your points are well taken. One of the things that you're pointing out that we really need to spend some time thinking about is that with the immigration of people who may not have the kind of family supports that many other seniors have, we need to think about what the implications are for our senior services system for seniors who, if they do require some assistance, will have families living at long distance from them.

SENATOR SINGER: Well, you can be the Florida-- The Florida syndrome is go home.

COMMISSIONER FISHMAN: Yes.

SENATOR SINGER: Florida provides virtually nothing and says, “Go back to where you came from. We don’t want to deal with you.”

ASSEMBLYWOMAN MURPHY: And we are the second most densely senior-populated state next only to Florida, and I don’t think a lot of people in New Jersey think of us as a haven for seniors. It’s kind of interesting when we have been the butt of so many jokes on late night shows. I guess all the seniors came to see why we’re so funny. (laughter) But at any rate, we are moving on.

And thank you very much, Senator, as always. You have been so very involved in this. And Sam has been so committed, as has Lou. So I’m fortunate.

DR. ROBINSON: Madam Chair.

ASSEMBLYWOMAN MURPHY: Yes.

DR. ROBINSON: I have a question.

ASSEMBLYWOMAN MURPHY: Yes.

DR. ROBINSON: I’m wondering about what impediments to alternative family care are posed by the boarding home law, and what is Senator Singer trying to accomplish with his legislation?

SENATOR SINGER: The problem is that presently right now in every township in the state, other than family members, you’re not allowed to have nonfamily members living in a private home. Adult foster care, which is a very good alternative for a lot of people, would be zoned out of existence. In other words, if you have two nonrelated family members in your house, you’re violating that rule.

We did something for -- through the State of New Jersey a number of years ago to help group homes. We said there is no zone they're not allowed in because we realized that people would zone those out of existence, also. We're going to have to do the same thing here. We're going to have to vote legislation that says adult foster care is allowed in residential zones because it really doesn't impede on a family, private-home situation. And that's the kind of legislation we're going to have to work on. If we don't do that, the problem is that many areas in the State of New Jersey just will never allow people to do that.

DR. ROBINSON: Okay. Thank you.

ASSEMBLYWOMAN MURPHY: I'm going to move on to our speakers. As you can see by the agenda that we have in front of us, there are a number of them. And we've compressed their presentations so that -- in order we may get the best of the best who are here.

I'm going to ask Gail Gibson Hunt if she would like to come forward. Gail. Gail is the Executive Director of the National Alliance for Caregiving, and she this morning will be giving us an overview of caregiving.

Gail, thank you very much for being with us.

**GAIL GIBSON HUNT:** Well, thank you for inviting me.

This isn't on. (referring to PA microphone) Is it? (affirmative response) Oh, great. Thank you.

(begin slide presentation) Just to give you a little bit of an overview --

I think it needs to be closer (referring to slide presentation). Well, I guess this is the best this goes.

The Alliance is a nongovernmental organization. We started in 1996, and we have now 14 national aging organizations that are part of our coalition. And our function is really to look at the whole issue of family caregiving, not paid caregiving, family caregiving of the elderly. We conduct research. We develop national programs to reach out to family caregivers, and we work on increased public awareness of the issues around family caregiving. And one of the pieces of research that we conducted last year -- that we published last year with AARP was a National Caregiver Survey, which is kind of the benchmark survey. The first survey of family caregiving -- random digit dial telephone surveys statistically representative of the country as a whole, the first survey that had been done in 10 years like this.

And I'm going to talk a little bit about the -- what some of the implications of caregiving are that have come out as a result of that survey.

We're almost to the edge here. (witness moving projector)

Just to give you all an overview -- these are all national data of course. For U.S. employees, it costs U.S. employers between \$11.4 billion and \$29 billion a year in terms of employed caregiving loss of productivity. The value of family caregiving, that is the value to society of the -- what family caregivers do, averages \$194 billion a year. And then there's a cost to the caregiver, him or herself, 73 percent of are women, so we'll say herself for the sake of this discussion. On average, those caregivers who are spending money out of pocket-- This is their own money that they're spending for things like medication or special home modifications or groceries or something for the older person. The average is \$171 a month, or we're talking about \$2000 a year, or the cost of what an IRA would be, perhaps.

The big statistic that came out of the National Caregivers Survey is the fact that there are 22.4 million U.S. households that contain a family caregiver, that is, somebody who is 18 or older who is caring for somebody 50 or older who needs assistance with everyday activities. That's about a quarter of the U.S. households. That number alone was enough to get a lot of publicity and a lot of attention in the national print media and television and radio media just because people didn't realize that it was -- there were that many Americans who were involved at doing caregiving.

And just as an aside, the 1987 survey that AARP had done when we -- using the same definition of caregiving -- compared with '97 and there was a threefold increase in 10 years of people doing family caregiving.

What are the characteristics of the typical family caregiver? It's a 46-year-old baby boomer woman right in the prime of her time of working and taking care of children. She's married. She spends about 18 hours a week doing caregiving. Now, this is going to run a whole span of tasks, and I'll talk a little bit more about what those tasks are, but it runs-- We're not talking necessarily that the 18 hours represents entirely hands-on personal care. That's also transportation and grocery shopping and helping with writing up bills and all. And she provides care to her 77-year-old mother, who has a chronic illness. So this is not like a one-shot deal or something that's going to happen for six months. It goes on an average of 4.5 years. Quite a few caregivers are caring for multiple people at the same time, so it's a mother and a grandmother and maybe a father-in-law, too.

Only about 20 percent of the caregivers and care recipients are what we call co-resident. The care recipient lives nearby, but not necessarily

in the same house as the caregiver. Just as an aside, co-resident caregiving is more stressful than non.

This will give you an idea of some of the kinds of hours and activities that caregivers are doing. The vast majority of people who responded to the National Caregivers Survey were doing at least one IADL. An IADL is an instrumental activity of daily living. That means something like grocery shopping or managing finances or transporting someone to doctors' appointments. ADLs, activities of daily living, are personal care. Those are the intense ones, bathing, dressing, feeding, transferring from bed to chair, wheelchair, wheelchair to bathtub, that sort of thing.

The most common IADLs were, as you can see, housework, grocery shopping, and transportation. Quite a few caregivers -- almost 40 percent -- help with medications. And this is a very important issue because -- particularly when you look at people with Alzheimer's, you see the need for somebody there to be sure that they're taking their medications because they don't remember.

We also, in our study, did a factor analysis. After we had done the initial survey and gotten the data back, we looked at what were the factors that contributed most to kind of an intensity of caregiving, the kinds of caregiving issues that would cause problems for the caregiver. And we found that two factors really were the biggest issues. One is the amount of time that you spend, and the other was the task that you're doing. So people spending the most amount of time and doing the most-intensive personal-care tasks, not surprisingly, were the ones who had the highest levels of care. So we had Levels 1 through 5, with 1 being the least-intensive caregiving and 5 being the

most intensive. And as you'd expect, on Levels 3 through 5, again the more intensive half of the scale, the care recipient has more trouble taking medications.

More than half of the caregivers were doing at least one ADL, one personal-care activity. And almost 30 percent helped with three or more. The most common of those were transferring in and out of bed, dressing, and bathing. Almost 20 percent of caregivers are providing constant care. That's 40 hours a week or more. As you can imagine, particularly when you start looking at people who are working and doing 40 hours a week -- and there are some people who are doing that -- you can see that that's going to create enormous stress on the caregivers. And another 7 percent did 21 hours to 39 hours a week.

In Level 5, we thought you might be interested -- represents 3 million caregivers nationally. They're most likely to be female, poor, older, and identified as being the principal caregiver, that is to say, the responsibility for caring. In this case, it's probably a spouse they're caring for, or it could be a mother. They're going to be doing the principal caregiving, and they average 56 hours a week.

We asked questions in the National Caregiver Survey about the use of services. And you can see here, these are the percentages of people who responded that they actually were using paid services of some sort with wheelchairs and walkers being at the top. There shouldn't come as any surprises -- actually home modification was higher than we would have expected. Transportation was lower, but then this is going to be a function of availability, as well as their knowledge of the service.

When we asked them, “If you’re not using a service, why not?”-- It was interesting, we thought, that most people really didn’t know about services, or if they did know about a service, they didn’t know what the service could do for them. So there’s a big information gap here for family caregivers. A lot of them say, “Well, we don’t need that service,” and that may be true, but it also may be true that they don’t know what that service can do for them. As you can see, almost 20 percent said they didn’t know anything about the service, so they never thought about it. And you can also see the cost was pretty negligible as a factor cited by caregivers for why they didn’t use the service, which came as a surprise to some of the people in the field.

When we asked what kinds of help they did think they would like to have, it was kind of surprising that almost 40 percent said, “They didn’t know. I don’t know what would help. I don’t have any idea how to formulate my thinking. I don’t know what’s available really, but I also don’t know what would help.” So again we saw the enormous information gap for reaching caregivers and letting them know. I mean, there’s a tremendous problem with caregiving, as you all probably know, and that is lack of self-identification. You can’t just go out there and say here’s a service for a caregiver and expect that they’re just going to come flocking because typically they’re just -- “I’m just the good daughter. I’m doing what any daughter would do. Or I’m just the husband. This is what I signed on -- for better for worse, for richer for poorer. So I don’t understand that I’m called a caregiver, and I don’t understand, when you say there’s a caregiver service out there, this is for me, this is something that can help me.” So there’s a real problem with outreach to caregivers letting them know what’s out there and what it can do for them.

Just to go quickly over some impacts on caregiving that we sort of summarized in the survey. They said their biggest difficulty was the demands on their time. Again when you think about the 46-year-old baby boomer woman, you can understand that. Almost 40 percent didn't know what services might help them -- had no idea. Most of them had used some formal services. Again the average out-of-pocket expenditures were \$171 a month, or about \$2000 a year.

The experience of caregiving as somewhat or very emotionally stressful was only mentioned by 25 percent of the caregivers. I think we need to be careful not to pathologize the concept of caregiving. Not everybody who does caregiving is burned out, stressed out, in need of psychiatric help. We need to realize that this is a normative activity. People really do continue to care for their parents and love their parents and work as a family in some cases to do that as well. So we need to have a balance here. Basically, this says that 75 percent of the people didn't find it particularly emotionally stressful, and only 11 percent said they found it physically stressful.

We would see caregivers benefitting from enhancing the care recipient's independence -- anything that you could do. Assisted living is perhaps one example. Some of these other home modifications and assistive devices to make the home environment better is something that would help enhance the care recipient's independence and, thus, help the caregiver and also, reducing the time, the cost, or the emotional toll of caregiving on the caregiver.

The other major study that we did looked at workplace implications. What's the impact -- we asked all kinds of questions -- on

working caregivers? Because, of course, employers are very concerned about that. These are just three trends that we saw. One is, in the last 10 years, there are more caregivers in the workplace because of more women working. There's more involvement. There's actually somewhat more sharing. This last point, an increase in male caregivers -- there are more men becoming involved in caregiving, which may be as a consequence of divorce. It's kind of hard to ask your ex-wife if she'll take care of your mother, who was her ex-mother-in-law. So there's really a sense of more men moving into the caregiving, and there's more negative impact on work. We're seeing more negative impact on work.

Just to talk a little bit about that, 64 percent of the caregivers work full- or part-time. Working caregivers said they spend an average of 12 hours a week providing care. And, incidentally, these statistics are all on the Caregiver Fact Sheet that I passed out. And about half of them provide instrumental activities of daily living only. That is they're-- So half of these people who are working caregivers are doing the things like taking mom to the doctors and doing grocery shopping and going over on the weekend and mowing the lawn and doing housework and that sort of thing. That does mean that the other half, however, are doing the personal care.

Here's a very telling list of what caregivers said they've had to do as a result of caregiving -- what impact it's had on their work life. About half of them go in late, leave early, have to take time off work as a result of caregiving. Eleven percent, surprisingly, actually took formal leaves of absence from work as a result of that. Six and a half percent actually quit their jobs. And that's differentiated from people who take early retirement. So the early

retirement is about 3.5 percent. Those are typically women whose husbands retire and maybe are ill, and the wife is near retirement age, and she takes early retirement. We wanted to really focus in and say how many people are actually quitting their jobs because they can't handle the caregiving and the job as well, and it's about 6.5 percent. It was kind of surprising actually given that there aren't that many employers who have corporate elder-care programs, but about 81 percent said that their employer was somewhat or very understanding of their caregiving concerns. (end slide presentation)

We did an analysis for MetLife of what the bottom line was for employers on this. When you look at the data that we've just shown, you combine the data that we've just shown on people taking time off and leaving work and passing up promotions and all that, and you translate that into dollars into terms of lost productivity for employers. If you just count the people doing personal care only, it's \$11.5 billion a year that it's costing U.S. employers. It's a relatively simple formula actually that you can multiply out to figure out what it was costing New Jersey employers actually, if you wanted to. If you count the people who are doing long-distance caregiving and you count the people who are taking time off from work to take mom to the doctors and those other kinds of things, it's \$29 billion a year nationally. So that was a figure that certainly had gotten the attention of a lot of businesses in terms of the big picture. And I just wanted to mention that sort of as an overview in terms of family caregiving.

We have a number of Web sites that are being developed partly in response to the needs of family caregivers. There's going to be a national leadership consensus conference that's coming up next month that's on family

caregiving. There are national groups like Suzanne's and others that are -- Developing Children of Aging Parents, which is based here or started here, in New Jersey, plus the Well Spouse Foundation and others that are getting started to begin to respond somewhat to the needs of family caregivers.

Long-term care insurance is beginning to have caregiver benefits. That's something where they're either giving stipends to caregivers, or they're giving educational grants to caregivers to learn more about how to deal with their caregiving. Or, in some cases, they're providing 800 numbers for them to get information. And then other organizations, such as Carol Levine's, are developing principles for health care and caregivers and the relationship between those two groups.

I just wanted to mention just in closing that -- what some of the implications are for the data about caregivers. There are three areas that I'm just going to mention. One is, obviously, family caregivers provide an enormous proportion of the long-term care in the country. Actually, 80 percent of the care of the elderly continues to be provided by family and friends. So it's incorrect to think that older people are being warehoused by their families in nursing homes because they're not. And it's really amazing and heartening to see how much families do, even as the expectations of their dealing with medical technology increases and with as little preparation and education as they have available to them. So greater public awareness and recognition of the value of their role in long-term care is a first step.

Secondly, as I've said, they need information and education. They need to know where to turn for disease-specific information on older relatives. Information about older-adult resources available in the community, like you

all were talking about -- but I'm assuming that those kinds of things under the New Jersey program are available to caregivers, as well as to the older person, so that that kind of information is-- And that caregivers can find out that they know this.

They need education, not just on the acute-care system with specific medical devices, but hands-on, everyday caregiver education: how to transfer somebody from the bed to a chair, how to bathe them, how to help with exercise, how to oversee medications. And they need information on how to plan for their own long-term care because the people who are today's caregivers are going to be the care recipients tomorrow, and that's all those baby boomers. Employers need incentives to provide greater access for their employees to elder-care information and services.

And, thirdly, as you all have recognized here in New Jersey, caregivers need respite. They need to have flexible time off from caregiving for a few hours to run errands or to have time for themselves or for longer periods to attend family functions, take vacations, continue working. Respite can be from a paid caregiver or can be through some volunteer at a local church group or a regular part of adult day care or some other way. But however it's provided, caregivers need to have some time for themselves and the other parts of their lives in order to continue doing the job that's a part of our long-term care system. So adequate support for caregivers now means fewer proportional outlays of public dollars for institutional care now and in the future.

Thank you.

ASSEMBLYWOMAN MURPHY: I'm very impressed. Thank you.

Susan Reinhard.

DEPUTY COMMISSIONER REINHARD: Thank you.

Gail, do you have any information on what any employers might be doing to help caregivers? Are there any good examples, any benchmarks that we could use for our state?

MS. GIBSON HUNT: There's lots of information about what good employers, the more sophisticated employers, the Fortune 500 employers are doing. They have corporate elder-care programs that include things like flextime, paid family and medical leave, not the unpaid family and medical leave, which really isn't used very much for elder care. They have information and referral services that they provide. But beyond the sort of sophisticated, maybe the more expensive services that corporate elder care can provide, there are low-cost, no-cost services, and I think it would be a valuable service to New Jersey employers to mention to them the fact that there are things that they can be doing that are low cost/no cost.

And some examples would be-- A lot of employers have already benefits in their benefit plan that they don't realize that they can use for elder care. Flextime would be one example; maybe dependent-care options; and they can just go through their existing benefit package, and they could kind of put it up on a little -- something that they could Xerox and give out to their employees and say, "This is what you can use for elder care. You can take a leave of absence. You can do job sharing, if you have to, for six months or a year," that kind of thing. That's an example. They can run ads in their little company newsletter -- not ads. They can run articles in the little company newsletter letting people know that we're sensitive to this issue. They can hold

caregiver fairs. They can get together with other little employers and hold caregiver fairs.

So there are a number of sort of low-cost, no-cost options that employers can take advantage of but I think takes away some of the feeling that this has to be something that only large companies can do.

ASSEMBLYWOMAN MURPHY: The survey that you say was done for the insurance company for MetLife--

MS. GIBSON HUNT: MetLife.

ASSEMBLYWOMAN MURPHY: Is that information available?

MS. GIBSON HUNT: Oh, yes. I brought, like, five copies.

ASSEMBLYWOMAN MURPHY: Wonderful. Wonderful.

MS. GIBSON HUNT: And as I said, if you want, the methodology for doing that is laid out in the report, which is really short, and you can plug in New Jersey's numbers and figure out what the cost is to New Jersey.

ASSEMBLYWOMAN MURPHY: Thank you.

Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: Would you repeat your definition of caregiver that was used for the study?

MS. GIBSON HUNT: For the survey, someone 18 or older caring for someone 50 or older who needs assistance with everyday activities.

ASSEMBLYMAN THOMPSON: I thought you simply said if there was someone 18 or older living in the home with someone who was -- was it 60 or over? -- and provides them services.

MS. GIBSON HUNT: No.

ASSEMBLYMAN THOMPSON: Or did I misunderstand you?

ASSEMBLYWOMAN MURPHY: I think you'd find it on this sheet, too, Sam, and that was in one of your packets, the National Alliance for Caregiving's fact sheet on caregivers.

ASSEMBLYMAN THOMPSON: Okay.

ASSEMBLYWOMAN MURPHY: And I think you'll find some of those typical statements that Gail used.

ASSEMBLYMAN THOMPSON: Well, maybe I misunderstood, but again I thought it was simply the criteria that there be someone 18 or over in the home with someone who was --

ASSEMBLYWOMAN MURPHY: No. That was the profile of the typical caregiver.

ASSEMBLYMAN THOMPSON: Okay. I'll look it over later.

ASSEMBLYWOMAN MURPHY: Let me know if you don't have this because I'll make sure you get a copy.

ASSEMBLYMAN THOMPSON: I think it's in there.

ASSEMBLYWOMAN MURPHY: Commissioner.

COMMISSIONER FISHMAN: Yes. I'd like to ask Gail a question.

First, I want to introduce someone else who has joined us, Carl West, who is the head of the Mercer County area agency on aging and the most senior triple A director in the country. And it just shows you that working this field can just help you age gracefully. Right, Carl?

Gail, my question is what in your view can the State of New Jersey do to most effectively convey to caregivers services that may already be

available to them that they don't know about? The insiders in this field know what's available. The problem is getting word out to folks who don't know much about the formal system of supports. What in your view is the best way for the State to communicate with caregivers to let them know it's available?

MS. GIBSON HUNT: Well, since 64 percent of them are working, I think you go through the workplace, and maybe you go through the APs, the employee assistance professionals. Those people, they take other areas similar to this. A lot of times they get involved with family support, family therapy. It fits right in, basically, with what they do. I think you could reach out through the employers. I think that's one big way that you're going to hit a lot of the people, and the employers ultimately will come around, be supportive of this as well. Although, it's not an automatic sell, I'll have to admit that.

The other thing is, we've given, as an organization, a lot of thought to this issue, and we know how difficult it is to reach caregivers. We've looked at libraries. I mean, we've sent out materials to all the public libraries in the country actually. People do turn to libraries for information like, "My mother's going to be coming back from Miami. Where do I look for housing?" And that's the kind of question they'll ask the reference librarian. That's an opportunity to give more information out than just specifically here the housing in this area -- here's the housing in this area.

Civic organizations -- and I've always thought that the PTA would be a good place to go as well. Because people who are in the PTA are already kind of attuned-- They start to be attuned to community activities and community resources, and if they aren't caregivers themselves, their parents

may be. So there you can -- going and reaching out through the PTA and groups like women's organizations, since this is a-- Clearly, it's a women's issue. Women's organizations are another way to go. And again, though, I'll just say from our experience, this is not an easy sell even to, say, the women's organization. But once you get the people in, you get a group in, say a focus group, they all say, "Oh, that's what you're talking about. Oh gosh, I wish I'd known that when I was caring for my grandmother."

COMMISSIONER FISHMAN: Is there a Web site that you think of as a particular good one?

MS. GIBSON HUNT: I think kind of the best caregiving Web site-- Well, the Administration on Aging has-- You know, let's give plugs to the Federal government. They have a good one. The Family Caregiver Alliance in California has an outstanding Web site that has wonderful suggestions for dealing with family caregiving. The only problem with it is it's California based. Incidentally, it's a model for any other state. But it's California based, and so the resource part, not the suggestions, but the resource part is California resources. But the other kinds of suggestions they have are really just outstanding.

ASSEMBLYWOMAN MURPHY: Thank you.

**C A R O L L E V I N E:** Can I just say one thing?

ASSEMBLYWOMAN MURPHY: Well, we're going to move on.

MS. LEVINE: Okay. Just quickly, don't forget the doctors and the nurses--

ASSEMBLYWOMAN MURPHY: Yes, the medical--

MS. GIBSON HUNT: All right.

MS. LEVINE: --who see the patients but never see the person who comes with the patient. That's a very primary link.

ASSEMBLYWOMAN MURPHY: Thank you, Gail.

Yes, Theresa.

MS. EDELSTEIN: I just wanted to ask a quick question. Is it possible?

ASSEMBLYWOMAN MURPHY: Go ahead. Go ahead.

MS. EDELSTEIN: In follow-up to what the Commissioner was asking about Web sites, in your surveying of caregivers, have you begun to ask them whether they have access to the Internet? Since the average age is 46, I would imagine that the number that have Internet access is probably growing. Do you have a sense of that at this point?

MS. GIBSON HUNT: Well, we didn't ask that question specifically on the survey, but the data are-- That's going to be something that really-- It's a gender-related issue. Women are much less likely to use the Web than men.

ASSEMBLYWOMAN MURPHY: That's right.

MS. GIBSON HUNT: And it's also an income-related issue, but certainly that's a direction that you can start to go, particularly if you're focusing on reaching people through the workplace. Because that's a place where some people have access to computers, that maybe they don't have it at home. So that's something to -- definitely a direction to move.

ASSEMBLYWOMAN MURPHY: Thank you again, Gail. We appreciate your being here, and we appreciate the material you have left with

us and the information. You've opened my eyes to a lot of things. Thanks an awful lot.

MS. GIBSON HUNT: Thank you.

ASSEMBLYWOMAN MURPHY: Suzanne Geffen Mintz is our next presenter.

Hi, Suzanne, how are you?

Suzanne is the President and Cofounder of the National Family Caregivers Association. She is speaking to us from the perspective of the caregiver.

Good morning.

**SUZANNE GEFLEN MINTZ:** Good morning. And thank you so much for this opportunity to address the Advisory Council on Elder Care. I want to commend you for recognizing the importance of caregiving and being farsighted enough to plan ahead to meet what is going to be an extraordinary need for programs and services in the years ahead.

I've been asked to share my own experiences of caregiving with you and to recommend what can be done now to help family caregivers and what will need to be done in the future. My own story began in 1974 when I was 28 years old. My husband, who was then 31, was diagnosed with multiple sclerosis. Now, almost 25 years later, he is in a wheelchair full-time and needs help with dressing, showering, toileting, transferring, and at times eating. I became a hands-on caregiver gradually over the years as the disease progressed. But from the moment of his diagnosis, I was thrown into the emotional maelstrom of caregiving, not knowing what to expect, always waiting for symptoms to appear, hesitant about making plans, not understanding that

we both were experiencing loss and needed to grieve. The emotional turmoil we experienced led us to separate twice -- once for a period of two years. I also suffered from two bouts of clinical depression, which is not an uncommon occurrence with some caregivers.

And it was because of my experiences and my desire to help other caregivers that I cofounded the National Family Caregivers Association. NFCA is the only charitable organization in the country reaching out to all of our nation's caregivers. Our mission is to improve the overall quality of life of America's family caregivers by providing information and education, support and validation, public awareness and advocacy. Our members care for spouses, children, aging parents, grandparents, and other loved ones. The majority care for someone over the age of 50 and have been providing care for five years or more. They are also providing intense levels of care -- Levels 4 and 5 on Gail's chart -- and this is designed to helping someone who needs help with two or more activities of daily living and providing care for more than 21 hours a week.

NFCA's members are typical of the 8 million to 9 million Americans who are providing extensive care at home for our neediest citizens. We surveyed our members in the summer of 1997, and the profile that emerged was rather scary. Sixty-one percent had self-proclaimed depression. Fifty-one percent suffered from sleeplessness. Forty-one percent from back problems. Sixty-seven percent say frustration is the emotion they experience most often. Forty-three percent say that isolation that comes with caregiving and the lack of understanding from others are two of its biggest burdens. The

vast majority, seventy-six percent, do not get consistent help from other family members.

These are the people -- untrained, unpaid, and at times very emotionally stressed -- that we, as a society, are relying on to provide care to our neediest citizens. Eighty percent to ninety percent of all long-term care is provided not by professionals, but by average Americans. Eighty percent to ninety percent of all long-term care occurs in the home, not in institutions.

Family has always cared for its own. That's nothing new. But today's caregivers are being asked to take on more and more responsibilities than ever before at a time when the nature of families makes it that much harder. There are multiple reasons for this. For one, people are just living longer. Today's elderly are living well into their 80s. Indeed, people over 85 are the fastest-growing segment of our society. Between 1960 and 1994, the number of individuals 85 years old or older increased by 274 percent. And as I'm sure you've heard before, persons over age 85 are more likely to have chronic illnesses and need personal care. In fact, 50 percent of all persons 85 years or older need some level of care.

Other reasons that caregiving is getting harder include the fact that medical science is creating miracles every day and people who need extensive care and treatment are being given extended lives. The problem is we're not looking at the social consequences of what medical science has been able to achieve. We're just sending people home from the hospital quicker and sicker than in years past and in the interest of cost containment. We're expecting families to manage and, in some cases, do procedures that used to be considered only the providence of medical professionals. We expect them to

do this without assessing their ability to cope, without finding out what resources, if any, they have available, whether it be financial resources with which to buy helpful goods or services or a support network to call on that can assist the primary caregiver.

I do not believe that there is malicious intent at work, but rather benign neglect, all of which, unfortunately, lead to the same end. Family caregivers are underserved and to some extent abused. I'd like you to hear from one caregiver in her own words.

Can we get the tape ready? (addressing VCR operator)

I'd like you to see what she's dealing with. Teresa Miller cares for her husband, Roy, who had a horseback-riding accident, much like Christopher Reeve did. They're both in their 60s. Theresa is what we call a 24-7 caregiver, 24 hours a day, 7 days a week. The only time she gets paid assistance is when Roy has a pressure ulcer because that is considered covered service by Medicare. All other times, she's on her own.

(video presentation)

What Theresa didn't say on the tape is that she has diabetes and high blood pressure, which she has to deal with herself. So the question is, what are we going to do today to help the Theresa's of America? What are we going to do in the years ahead when there are so many more people in need of care and far fewer family caregivers around to help them?

The Census Bureau projects that by 2030 there will be six potential informal caregivers for each person in need of assistance. They expect that ration to dip to four-to-one by 2050, when the peak of baby boomers is in their 80s. In comparison, back in 1990, just eight years ago,

there were eleven potential caregivers for each person needing care. The need is going up, and the number of people available to fill it is going down.

The problems are complex, and there is no single answer. We need to attack the problem on multiple fronts. There is a role for government, for the health-care system, for communities, and for employers. We are truly headed for a caregiving crisis unless we adopt a proactive approach to dealing with the issues surrounding long-term care. I believe there are a number of things that we can begin doing. We must recognize that families are not professionals or the principal providers of long-term care and that the home and not institutions are where most persons in need of assistance live. We must, therefore, remove the current financial bias toward institutional care and reallocate funds to support community-based programs, as you are doing. We must acknowledge that caregiving is outside the norm, that it comes on top of other responsibilities, that it can last for a very long time, and that it changes.

A family may need one service today and have a very different requirement tomorrow. A family may be able to cope for three years, but six or seven will put them over the edge. My needs as a caregiver are different from those of my 80-year-old mother, who is caring for my 85-year-old dad, who has dementia. And both of ours are different still from a sandwich generation caregiver raising a teenager and, simultaneously, caring for her own mother. In short, all programs for family caregivers have to be extremely flexible. We have to trust families to do what is right and not create systems of very specific regulations that cannot respond to changing circumstances that strangle rather than support, that make life harder rather than easier. In short,

we have to give caregivers and care receivers the power of the purse and the power to make decisions that work for them.

There's actually a model program that is scheduled to be launched in New Jersey that meets many of these criteria. The overall Program is called Cash and Counseling and is a joint partnership between the Assistant Secretary for Planning and Evaluation at the Department of Health and Human Services in Washington, HCFA, and the Robert Wood Johnson Foundation. It is actually directed toward care recipients, not caregivers, but it will be beneficial to both. The Demonstration, which is called Personal Preference in New Jersey, will enable thousands of older and younger people with severe disabilities who are Medicaid eligible for personal-care services to receive a cash allowance to purchase goods and services in the marketplace, rather than be forced into preestablished modalities. Counselors will help provide referrals and a cash management plan for care recipients.

Depending upon level of competency of the Program participant, a family caregiver may serve as the responsible representative making decisions. The intent of the cash allowance is to enable disabled recipients to manage their own arrangements by eliminating the middleman so that services can be tailored to the individual needs and circumstances of care recipients and caregivers. For instance, funds can be used to purchase respite for a family member providing caregiving services, or they can be used to make a home more accessible or even pay a family member to be a personal-care attendant.

The New Jersey Demonstration Program is scheduled to get started in 1999. Bill Bido (phonetic spelling) is its director. The Cash and Counseling Program seems to me to be a great idea, but it will be a long time before results

of the demonstration project are know. And it is only available to a specified Medicaid-eligible population. We need more broad-based programs that can be enacted quickly to help caregiving families.

Not all caregiving families need financial assistance, although most would benefit from it, but something all caregivers need, regardless of their financial status, is guidance, referrals, and a friend they can call on at critical moments. In caregiving, as in other aspects of life, there are stages. There are crisis stages, there are plateaus, there are points of transitions. We have to recognize that during times of crisis and times of transition are when caregivers need the most help. It is during these times when new circumstances are throwing life out of kilter that caregivers are most stressed and most at a loss to where to turn.

During these crises and transitions, it would be very beneficial for a caregiver to have a care counselor to turn to: Someone who will say, “Don’t worry, I’ll help you.” Someone who isn’t emotionally involved, who has access to a database of public and private resources. Someone who can provide guidance to help caregivers make decisions and establish a plan that will lead to a new normalcy for the caregiver and her care recipient. It is the counseling part of the Cash and Counseling Program. If there is a way to give all caregivers who want it access to such a service, you would truly be doing something beneficial, something that I believe in the long run will also prove to be cost effective.

Thank you.

I’d like to respond to some of the questions that you asked Gail.

ASSEMBLYWOMAN MURPHY: Well, we had new ones for you, but that's okay.

MS. GEFFEN MINTZ: Well, that's okay, too.

About how to reach caregivers. I'm a big proponent of public awareness. People watch television, and they are more likely to pick up things on the airways -- easy ways that just come into us rather than ways that they have to seek out. So whether it's public service announcements, whether it's working with national media to get more stories about caregiving in the local news but just to get the message out there and to literally ask people, "Are you caring for somebody who is ill or disabled? Then, you are a family caregiver," because we need to make that connection. Because, as Gail said, self-identification is one of the big issues. So I'm a big proponent of mass media myself.

And I agree with her that the Family Caregiver Alliance is a very good Web site. We have gotten compliments on ours. The site address is [www.nfcacares.org](http://www.nfcacares.org) -- all lower case.

ASSEMBLYWOMAN MURPHY: [N-F-C-Acares.org](http://N-F-C-Acares.org).

MS. GEFFEN MINTZ: [Dot.org](http://Dot.org).

COMMISSIONER FISHMAN: [N-F-C-Acares.org](http://N-F-C-Acares.org).

MS. GEFFEN MINTZ: NFCA, for National Family Caregivers Association.

ASSEMBLYWOMAN MURPHY: Okay. I'm going to take the option to ask you a question.

Suzanne, do you find that the majority of the caregivers that you are dealing with through your support group are people who are dealing with

someone in their home or in the person's own home? In other words, does the caregiver-- Is this person I'm caring for someone in my home, or am I going to their place of living?

MS. GEFFEN MINTZ: The vast majority of people we are dealing with are caring for someone in their own home that they cohabitate.

ASSEMBLYWOMAN MURPHY: Right.

MS. GEFFEN MINTZ: And they're providing lots of care.

ASSEMBLYWOMAN MURPHY: Yes.

MR. MUNIZ: I have a question. Thank you. It's not a question. It's more or less a comment. I saw Teresa providing the services to her husband, Roy, there. And I saw through the video the capability of being able to do it to a certain extent. She had the apartment or the house and she had enough space, and I was kind of glad to see that, but what about those people who live in one-bedroom apartments/two-bedroom apartments that don't have those capabilities of taking care of the person. They don't have the knowledge to learn -- the easiness to learn how to take care of the loved ones, and they don't understand the language in order for them to learn how to provide that service to their loved ones, and so on. I think that-- I feel very hard for Teresa, but there are other people way, way worse than Teresa is, and those are the people we also have to keep in mind when we're thinking about caregivers -- those people that don't have the availability of doing it because of the language or because of the space available to take care of those individuals in their homes.

MS. GEFFEN MINTZ: I think we have to be extremely sensitive to cultural differentiations in care, that programs need to be accessible and in

multiple languages. It gets down to that question of flexibility. Different people need different kinds of help and different levels of intervention.

MS. MICHELSEN: Madam Chairwoman.

ASSEMBLYWOMAN MURPHY: Renee.

MS. MICHELSEN: This question is for Suzanne and perhaps for Gail. You can address it as well. You frequently mentioned training, that the caregiver is untrained, thrown into this, it's unplanned, and we all know that. Throughout time, the State has given small grants for caregiver training seminars, sessions, learning groups. Do you think that those sessions are of value? Do you think caregivers would attend very often like five sessions -- that type of thing? Do they want more training? Is that something we should put money into, training them?

MS. GEFFEN MINTZ: It's a double-edged sword. Yes, we need some training. Whether people are actually going to get and go five weeks in a row I'm not sure. I think things need to be available to people on multiple levels, but I think caregivers need information at specific points in their lives. Also--

MS. MICHELSEN: But information is different than training.

MS. GEFFEN MINTZ: That's right.

MS. MICHELSEN: We know about information but--

MS. GEFFEN MINTZ: But you need different training at different times.

MS. MICHELSEN: Right.

MS. GEFFEN MINTZ: Just in my own experience, we're needing more help with transferring now. It wasn't an issue for me 10 years ago. It's

an issue for me now. And the thing, quite frankly, that's been the most beneficial is having an OT come into our house and actually see what our circumstance is. Going to a class and seeing something in an arbitrary setting doesn't relate to the circumstances of my-- Caregiving is very individual. And so, yes, it's important to get generalized training. But ultimately, I think a lot of it is one-on-one at a time when you need it. Because-- When you're needing the training is probably when you're under a great deal of stress. Half of it goes in one ear and out the other. So it's like for me learning computer stuff. Don't teach me everything. Teach me this one skill, and I will learn that, and I will go on to the other. So you've got to look at it in that way.

MS. MICHELSEN: So what you're saying is that the training needs to be flexible, as opposed to set sessions. So that if CCPED had like an element of it where a TO or a PT could come into your house if you developed that need and give you one or two sessions on how to better handle the person you were caring for, that would be helpful.

MS. GEFFEN MINTZ: I think that's the most beneficial.

MS. MICHELSEN: Okay. Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much, Renee. Let me introduce Senator Norm Robertson, who has joined us now.

Thank you very much for being here.

SENATOR ROBERTSON: I apologize for the hour. I, unfortunately, was stuck in North Jersey today and unable to get down--

ASSEMBLYWOMAN MURPHY: Those things happen.

SENATOR SINGER: Move south. (laughter)

Just one question. For instance, what you talked about mental health, should there be a segment of this in mental health dollars for caregivers for depression, for all the things that -- for counseling? Are we lacking that?

MS. GEFFEN MINTZ: Well, having been there myself, I think where we need to begin is to get the medical community to begin to assess caregivers. I think the question needs to be asked, when somebody goes for an exam, are you a caregiver? And it doesn't mean that there's going to be a pathology, but they should at least begin to see that if somebody's a caregiver, they should be open to looking at what might be going on with that person's life. And I do believe that caregivers who are at risk should have access to mental health services, yes.

ASSEMBLYWOMAN MURPHY: Thank you very much.

DR. ROBINSON: Madam Chair?

ASSEMBLYWOMAN MURPHY: Yes, Joanne.

DR. ROBINSON: Suzanne, I'm thinking about targeting those caregivers at greatest risk. And you said that most of the caregivers connected to your organization are doing it alone -- are independent caregivers. Do you find that those who are part of caregiving networks or teams, perhaps teamed up with other siblings or neighbors, etc., seem to bear a little bit better, or is there conflict among the members, etc.? Are they at less risk? And if that can be facilitated, would we do everyone a favor?

MS. GEFFEN MINTZ: Caregivers who have support systems -- they're better. If there is a really cohesive family and they're sharing the care, that's very beneficial. What we hear a lot is, "I have three sisters and they don't do anything." When people can put together systems of care, which can

be family, which can be friends, it lessens the isolation. It means that you know that you've got somebody to turn to in an emergency. On the day-to-day level, those are the things that help.

I don't have family nearby, but our neighbors are very supportive. I know that I can call the guy across the street and the guy next door when Stephen falls out of his wheelchair. I can't pick him up. But at a moment's notice, they'll come over. That is priceless to me, and that has nothing to do with insurance. It has nothing to do with dollars. But what it does have a lot to do with is getting people comfortable with the idea of asking for help. Getting people comfortable with letting other people come into their very personal and intimate lives, and that in itself requires education. I'm willing to tell my story to anybody, but it's something I had to learn. And there are many people who will not and, if you don't reach out, may also not accept even if it's offered.

ASSEMBLYWOMAN MURPHY: Thank you very much.

Assemblyman.

ASSEMBLYMAN ROMANO: Just a fast comment. I couldn't agree with you more when you talked about public awareness. You have to get the message out there, whether it be church bulletins, whatever the case might be. And in another sense, I noticed there are people here from other counties who are involved with senior citizens. And I know, for example, Dr. Tolliver goes around-- If you have more than 10 people there having a cup of coffee and a piece of cake, Dr. Tolliver will come to speak about the Division on Aging.

Am I correct, Dr. Tolliver? (*sic*)

ASSISTANT COMMISSIONER READER: For me, Ruth Reader?

ASSEMBLYMAN ROMANO: Yes.

ASSISTANT COMMISSIONER READER: Yes. Absolutely.

ASSEMBLYMAN ROMANO: Because I've seen you at the events, that's why I'm talking about it.

ASSISTANT COMMISSIONER READER: Sure. Goodness yes.

ASSEMBLYMAN ROMANO: Let's put that to the side -- if you had people of that caliber. But also, as I read and listened to you when you talked about the Cash and Counseling Program, it was fine up until I turned the page, and then it said, "Only for a Medicaid-eligible population." Too often, we are looking at Medicaid as the cutoff. Everything is Medicaid. Just like in the State of New Jersey when people talk about means testing, they talk about the PAAD limits. There are a lot of people who are just above that, and that's something that we have to take a look at in terms of helping people who are beyond the cuts, which are not really a fair measure of someone's wealth or whatever the case might be.

And also, what we're talking about here is when someone is leaving -- and usually depending upon the deformity or the impairment of the elder person, they're coming out of a hospital more often than not. That exit plan that's supposed to be provided by the doctor with the social worker, with the staff of the hospital goes a long way in preparing the family as to what they should do when they get this person home. Now, also with that-- And this also gets tied into-- We have Commissioner Fishman here, who has direct access to Medicaid and Medicare, etc., that these would be allowable costs under Medicare that a doctor could have.

Let's say we're going into a different stage, and the doctor would suggest that the visiting nurse comes and gives -- how should I put it? -- the training or the counseling on how to handle the patient in this particular phase. And also to determine the type of apartment, which someone had mentioned, which goes a long way for the psychological factor that the person is in and maybe suggesting very emphatically, "Move out of here. This is not the place you can spend several years of your life." Everyone wants to get to the outside to smell the flowers and get some fresh air. And then you run into, can they get out of the building, or does it require the EMS services to come up and take you down with a stretcher? So we're talking about the ADA.

It's so broad. But everything that we look at-- Any plan we make along any area we all have to have the common sense to plug in all these issues, whether it be housing, whether it be exit plans from the hospital, whether it be church groups or speakers to go around. We just have to try to use our best sense to make sure everybody knows what they can do and what they shouldn't do, etc.

ASSEMBLYWOMAN MURPHY: We do.

Thank you very much, Assemblyman.

We're going to move along.

Suzanne, thank you so much for your insight--

MS. GEFFEN MINTZ: You're welcome.

ASSEMBLYWOMAN MURPHY: --and the personal touch, I guess, that you bring right to bear with it. Thank you.

Suzanne Linnane. Have I said the name properly?

**S U Z A N N E L I N N A N E:** Yes.

ASSEMBLYWOMAN MURPHY: Suzanne is here. She is a specialist in the State Policy Clearinghouse of the Alzheimer's Association. She'll be speaking about policy issues for the future and what other states are doing.

Good morning, Suzanne.

MS. LINNANE: Good morning.

My name is Suzanne Linnane. I'm a State Specialist in the State Policy Clearinghouse in the national office of the Alzheimer's Association. We're located in Washington, D.C. The purpose of my presentation is to provide you a broad overview of how states can support the role of caregivers and the needs of caregivers, particularly those caring for a person with Alzheimer's disease.

Our Association has three strong chapters that are located in the State of New Jersey. They have worked as partners with the State to support caregivers.

Can you hear me? (referring to PA microphone; affirmative response from Council)

Our Association has three chapters in the State of New Jersey, and they have worked as partners with the State to support caregivers. The chapters are more capable of speaking to the specifics of the needs of New Jersey. I'm here to provide you a more broad overview of the needs of caregivers in the role that the State can play in those sort of supports.

The following statistics provide a startling picture of our caregivers, and you've heard some of them earlier today. At least 70 percent of people with Alzheimer's disease live at home. Seventy-five percent of their care is

provided by family members. So of all caregivers, nearly one in five is taking care of a person who has some form of dementia. That's 5 million caregiving households nationwide. Caring for a person with Alzheimer's disease is a 24 hour, seven day a week job. A person caring for an Alzheimer's patient averages 69 hours per week, and most of those people are working. Also, Alzheimer's caregivers spend approximately 4.1 years -- an average of 4.1 years caring for a person with Alzheimer's disease.

Studies show that Alzheimer's caregivers tend to be older. They provide more hours of care over longer periods of time, and they meet heavier care needs. They are more likely to deal with incontinence, managing medications, and assisting with all activities of daily living. They report high levels of emotional and physical stress, and they are twice as likely to report physical and mental health problems.

I guess the question is, why should State support caregivers? And you've heard a lot of evidence this morning about that. In survey after survey, caregivers indicate that what they need most is a break. That's exactly the purpose of New Jersey's Program. That in itself should be reason for public policies to support caregivers, but there are financial reasons to do it as well, particularly for states that are concerned about the size of their Medicaid, long-term care expenditures.

A recent study by Project Hope researchers and Harvard School of Public Health showed that delaying institutionalization of an Alzheimer's patient by as little as one month can save \$1.12 billion annually. The study also found that a one-month delay would save on average \$1863 for an Alzheimer's patient. The study also found that substituting assisted-living

facility care for nursing home care could save \$3.5 billion to \$5 billion annually. So respite care can delay the cost of expensive nursing home placement, while allowing families to keep their loved ones at home.

Caregiving also impacts businesses. About 60 percent of Alzheimer's caregivers are employed outside the home and about two-thirds of those employed caregivers said that they had to make work adjustments to meet their caregiving responsibilities. The Alzheimer's Association came out with a business impact report in September, and it found that Alzheimer's cost American businesses \$33.16 billion a year. That's based on caregiver absenteeism, productivity loss, replacement of caregiver costs, and the business share of medical care and medical research costs. Absenteeism of caregivers alone accounts for \$26 billion of this cost.

These numbers are obviously expected to grow as the baby boomers become older. On New Jersey, specifically -- you already heard New Jersey has 1.4 million senior citizens, one of the largest senior populations, in the state. One in seven of your residents is over the age of 65, and 159,708 people in your state have Alzheimer's disease. The number of residents-- There's about 30 percent of people in New Jersey that are in the baby boom generation, which means in the year 2020 that there's going to be a 30 percent increase in the amount of people over the age of 65. And statistics show that one in ten people over the age of 65 and half of the people over the age of 85 have Alzheimer's disease.

New Jersey has been a leader in innovative programs to help caregivers. This year's \$1 million appropriation indicates that strong support of caregivers and your commitment to that.

I've been asked to comment specifically on what other states are doing to help caregivers. But as a leader in such programs, it's not likely your State is going to learn a tremendous amount from other states. In fact, when people do call our Association and ask how they can improve their caregiving support systems, we generally refer them to the New Jersey model. However, one thing that New Jersey can do to strengthen the Program is reduce current waiting lists and to increase the payments to caregivers to meet the long-term care costs increases over the years.

Other states-- Well, a few examples of what other states are doing are home modifications and assisted devices -- they provide reimbursement for them. Pennsylvania is one of the states that does that for their Family and Caregiver Support Program. They provide \$2000 -- a one-time payment of \$2000 per client for modifications made to the home. And four out of ten Alzheimer's caregivers had modifications made to their home to make caregiving easier.

Other states provide outreach support and training for caregivers. Less than half of caregivers say that they were taught to do their job. About 42 percent say that they were told how they should provide their care. There are a couple of states that have resource centers. California has a Caregiving Resource Center, and New York has a Caregiving Resource Center. These Centers provide information, training, counseling, support, coordination with other groups, community education, outreach, libraries, and advocacy among a host of other things.

One handout that I've given you, and I apologize because I did not bring enough, so you might be getting it a little bit later, is a study of 15

programs. They are under the Alzheimer's Demonstration Grant Program, and it discusses 15 states and what they are doing to help caregivers under this Program. They're essentially targeted to hard-to-reach populations, which we discussed earlier, cultural and ethnic minorities, and also rural areas. So the descriptions of these programs might be something that New Jersey could look to in answering some of those questions and, finally, creating a system that provides affordable assisted-living facilities so that when families are overburdened that they have an option for when the caregiving becomes too overwhelming.

Finally, I'd like to comment on two proposals that are offered as alternatives for supporting caregivers, and I'd like to urge a little bit of caution about them. One is tax credits for caregivers. Federal taxpayers can already deduct all of their long-term care expenses as medical expenses, and many states allow similar deductions on state taxes.

In a number of states and occasionally at the Federal level, tax credits are proposed as a simple way to provide some recognition of caregivers. The simplicity of the concept, along with the popular appeal of tax cuts, makes this an attractive idea, but it's important to consider realistically how much help it can really provide. For instance, the tax credit would really only help a small group of people because only 30 percent of seniors are paying taxes. And a tax credit of \$500 could also be quite costly to the state. It might be better put into resources to increase the respite care program and other support services to caregivers.

Finally, long-term care insurance. Many people hope that private long-term care insurance is going to solve a lot of the problems of increasing

long-term care costs. And we agree that people should consider long-term care insurance as one tool for retirement planning. The long-term care industry is focused on marketing to people in their 40s and 50s when premiums are lower. Sometimes employers are offering that as part of their package for insurance, but they usually don't pay the premium. But even if insurers are successful at marketing to these groups, it will be 30 to 40 years before these people start collecting on their policies. Therefore, it's not going to solve the immediate problem of long-term care costs, which are rising quite rapidly.

Another factor to consider is that only 6 million people currently have long-term care insurance policies, and that's partly due to the fact that even the most optimistic studies indicate that it's not affordable for most segments of the population. And there are also some restrictions based upon disability at the time of underwriting, which also limits some people's access to that type of a product.

All of us here on the panel today have a similar message, which is that caregivers need our support and that they're doing a very valuable job for our families and for our society. We can't afford to lose that. It's a need that we can meet together through government and voluntary organizations like the Alzheimer's Association, employers, and health-care providers. It's one of the most important things that we can do together.

On behalf of the Alzheimer's Association, especially our chapters here in the State of New Jersey, we'd like to thank you for having us here today.

ASSEMBLYWOMAN MURPHY: Thank you very much, Suzanne. We appreciate your being here.

Did you have a question? Commissioner.

COMMISSIONER FISHMAN: Suzanne, can you give us a sense of some of the common modifications or assisted devices -- I don't know if that hands-on stuff falls within your purview, but what are some of the common things that make a difference?

MS. LINNANE: Well, I think clearly modifications that could help the person that needs the care. But also one thing that I have heard about that I found interesting was a caregiver that had severe asthma. She had to move into her mother's home to care for her, but in order to do so, she needed air conditioners installed in the home. And that's something that at kind of a low cost, you can still get a caregiver in there and avoid costly nursing home placement.

COMMISSIONER FISHMAN: So some of these things are actually targeted the caregiver.

MS. LINNANE: I think that's probably in the minority of cases. They're probably more geared normally towards the person needing the care.

MS. MICHELSEN: Suzanne, do you mean simple things like Wander Guard?

MS. LINNANE: Yes.

MS. MICHELSEN: I think that's the kind of thing that if that was factored in as a reimbursable type of service that that would be very helpful.

MS. LINNANE: And I have something on Pennsylvania's Program, too, if you'd like to see that.

MS. MICHELSEN: Does the Pennsylvania Program pay for Wander Guard or a similar product?

MS. LINNANE: Well, probably a similar product -- home modifications and assisted devices they'll reimburse for.

ASSEMBLYWOMAN MURPHY: If you have information that you'd think we would be benefitted by, Suzanne, we'd be happy to have it and make copies available to all the members who are here.

MS. LINNANE: Okay.

ASSEMBLYWOMAN MURPHY: If there are no other questions, I thank--

SENATOR SINGER: Just one quickly.

ASSEMBLYWOMAN MURPHY: Yes, Senator.

SENATOR SINGER: Do you have a kit that you send out to someone who calls and wants information? In other words, if I called your offices, do you have a kit that you send to me as a caregiver for an Alzheimer's person?

MS. LINNANE: Generally, that is what our chapters do.

SENATOR SINGER: Can we get a copy of a kit?

ASSEMBLYWOMAN MURPHY: Could we reach one of your chapters?

SENATOR SINGER: I would like to see-- Can you just contact one of your Jersey chapters to send us a kit of what they would send somebody who calls up and says, "Look, my loved one has Alzheimer's. I don't know what to do. Can you help me?"

MS. LINNANE: Yes.

SENATOR SINGER: Okay. I'd appreciate that. Thank you.

MS. LINNANE: I'll get back to you.

ASSEMBLYWOMAN MURPHY: Thank you very much, Suzanne.

MS. LINNANE: Thanks.

ASSEMBLYWOMAN MURPHY: Thank you very much. I appreciate your coming today and taking your time to testify before us.

MS. LINNANE: Thank you.

ASSEMBLYWOMAN MURPHY: Steven Zarit, Ph.D. Steven is the Assistant Director of the Gerontology Center of Penn State University, speaking today on research study with DHSS on benefits of adult day services on family caregivers.

Thank you very much, Doctor.

**STEVEN H. ZARIT, Ph.D.:** Okay, thank you.

I'm going to stand back here so I can see the slides (begin slide presentation), hopefully, as well as you'll be able to.

I want to start by picking up on something that Suzanne Mintz said a while ago, which I think is terribly important for setting the context of understanding the problems that caregivers face. And that is that the situation in many ways is unprecedented. The people are taking care of individuals with more complex, more demanding care needs than ever before. And that's the reason why families who are facing heavy care needs from severe problems -- Alzheimer's, other degenerative diseases, other neuromuscular disorders, injuries, traumas, and so on -- why these caregivers are often under such considerable stress.

The key issue and the issue that everybody has been talking about this morning is how can we help families so that the demands on them don't become overwhelming -- what are effective ways of sharing the care so that families can carry out their responsibilities more effectively. For the past seven years or so we've been involved working with the Department of Health, now the Department of Health and Senior Services here in New Jersey, conducting a study of adult day care, specifically, trying to see what kind of relief adult day care brings for family caregivers of someone suffering from Alzheimer's disease or other progressive dementias.

You might say that day care ought to be effective. Of course, if you provide help for several hours a day that ought to help the caregiver. When we began the study, we reviewed the available literature very carefully and found that the existing studies tended to suggest that day care and other respite services, if they were effective at all, really were only providing a little bit of help. When we looked at those studies very carefully, we found that one of the reasons that may have been contributing to the problem was the fact that they had been providing very little help at all to these families.

The best study to date, when we were developing our study -- have been providing one day of day care a month to family caregivers or an equivalent amount of in-home respite. And so when they reported that respite services helped little or not at all, we were concerned that that was the wrong interpretation, that the problem was really that families weren't getting enough help.

In the study that we designed, one of the things that we were concerned about was that families do get sufficient help. And everybody who

was enrolled in our study was receiving adult day care at least two days a week. The typical pattern was three days a week. And some families, particularly families with an employed caregiver, were receiving day care five days a week.

Let me tell you a little bit about how we conducted the study. We received referrals. We had actually 45 day cares throughout New Jersey that agreed to participate in the study and 36 eventually sent us referrals of people who were eligible for the study. We got families at the point that they began using day care. We evaluated them. We came back three months later and evaluated them again and then evaluated them after one year.

We needed a control group and felt we couldn't do a random assignment or couldn't take people in New Jersey who selected not to use day care because that would be a bias group. So we went to Ohio. Northeastern Ohio matches up on many sociodemographic characteristics well with New Jersey. But at the time we started the study and, in fact, even today has a fairly undeveloped network of adult day care. So we felt that people in Ohio who weren't using day care were an appropriate comparison group because they had a much more limited opportunity to use adult day care for their relatives.

We evaluated them on the same schedule, so we have parallel information on people from New Jersey who were enrolling in day care for relatives with Alzheimer's disease and people in Ohio who were not using day care for relatives for Alzheimer's disease.

Let me tell you a little bit about our sample, and this is fairly similar to the information you've been hearing from other presenters on characteristics of caregivers. Our sample consisted of about -- slightly over 40

percent were spouses of the person they were caring for, over 40 percent were children, and then we had a group of other caregivers. Twenty percent of our caregivers were men and 80 percent women, again fairly typical. The mean age of our caregivers was around 60. The mean age of the person they were caring for was about 78. So a fairly old group.

Now, did adult day care make a difference? We used two sets of measures. The first set is what we called primary appraisals of stress. These are stress indicators that are embedded in the daily routine of care. It's stress related to the ongoing effort that a caregiver makes in assisting a relative with dementia. We have three measures of these primary appraisals and found that in two of the three measures, day care use was associated with significant decreases of stress in those areas.

The first one is what is called overload, having more to do than you could possibly do over a 24-hour period, a very typical situation for caregivers. What you can see is caregivers using day care showed a decrease in overload in the first three months. Caregivers not using day care showed an increase.

The second measure was a measure of caregiving strain, which is the psychological stress and tension, again associated directly with everyday care routines. We found a significant decrease in strain for people using day care and virtually no change for people in the control group.

We had a third measure called role captivity, the feeling that you were trapped or stuck in your role as caregiver, and that measure showed no difference over time.

So in two of our three indicators of direct caregiving stress, we saw that day care resulted in significant improvements for family caregivers. The other set of measures that we included were measures of general well-being. We included those because we felt that we had to be comparable to other caregiving studies, but we didn't hold out much hope because we didn't regard adult day care as a treatment for depression. There are lots of established treatments for depression, but adult day care isn't considered one of them. But this is where we had a surprise in our study. That we found again on two of our three measures of well-being that people using adult day care had significant improvements.

On depression, which is over here (indicating slide), you can see there was a large decrease in depressed feelings for caregivers using adult day care in the first three months of day care compared to an increase in the sample not using day care. This is a large and statistically significant difference. If this were a drug, it would be rushed into production. (laughter)

We had a measure of caregiver anger, which is often an overlooked emotion. Caregivers -- a lot of things in their situation make caregivers angry, and we found a significant reduction in anger compared to the control group. We had a measure of positive feelings -- in here increasing is good rather than decreasing. Although we showed some increase in positive emotions, this wasn't a significant difference.

Now, these are the findings for three months. We continued to follow people for a year, and we found a fairly similar pattern. Again first for our stress measures, our appraisals of caregiving, you can see that was a -- continued after a year; a decrease in overload; compared to the control group,

that was significant with respect to strain; and role captivity we didn't have significant results after one year; although, the effects, the direction -- it's going the right way.

With respect to well-being, again, we still saw an effect for depression after one year. And I think what's notable here is not only that people using adult day care were less depressed one year after using it, and these are people still continuing to use it -- their depression was much less -- but in our control group, their depression has gone up even more than it had been at three months. So it's very clear that people getting this kind of help are benefitting in some very specific ways related to the care routines and then in some general ways in that their own well-being is improved over time.

One of the other things that we did is ask the caregivers who are using day care for their evaluation of the services. What did they think about the program? What helped them? What didn't help them? And overwhelmingly they were positive. This was one indication-- This was a general question about how satisfied you are with the services that you're receiving (indicating slide). And what you can see is that 78 percent of our sample selected the extreme point of being very satisfied. And on virtually every question that we asked, we got similar proportions of people who were overwhelmingly satisfied or very satisfied with every aspect of the program that they were receiving, the quality of the care that was provided, the nature of the facility. Even with the cost of the facility, which tended to produce a little more dissatisfaction, we still found that most people were overwhelmingly satisfied.

One of the other interesting things that we found is that people-- We asked caregivers about what the effect of day care might be on their ability to manage their relative, and they said some interesting things. One thing they said was that they really didn't have a lot of problems in the morning getting their relative to go. That's an issue that often is a barrier for families to use day care. They think that they'll have trouble getting the patient dressed and out, but in fact, once a routine is established, families are able to carry that out without a lot of stress. The other thing that we found is that caregivers said that their relative was easier to take care of after they spent a day in day care. In fact, one caregiver told us, "My husband comes home, and we now have something to talk about," which was an interesting finding in itself.

The idea of being in a structured program during the day may actually be beneficial to patients as well as to families. And that's something that we will be following up on in a new study that we'll be doing, hopefully, beginning after the first of the year to try to see what are the specific effects and benefits that patients might receive by attending these day care programs.

The one important caveat to these findings is that many of our families use day care very late in their relative's disease process. It's consistent with what the other presenters were talking about today, that families don't get this information in as a timely a way as they might. In fact, one of the things that we knew from pilot work that was done in the Department of Health and Senior Services was that many of the people who start using day care stop relatively quickly because the relative is too sick, and day care for these people is really a last gasp, and it's not enough at this point. And the family member soon ends up in a nursing home. We found that about 30 percent of people

enrolling in day care programs, which was about what we had expected, are soon out of those programs, and many of them end up in nursing homes. Clearly, families don't get the information early enough and aren't using day care in the most optimal ways in many situations. (end slide presentation)

Let me stop at this point and see if there are questions. The technical report went around, and I'd be glad to provide other supplemental information, or Rick Greene can help provide some of that information for you.

ASSEMBLYWOMAN MURPHY: Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: I note in your study the long-term panel that the mean age of the caregiver that utilized the day care was 56, while the mean age of the control group was 61, a five-year difference, while the age of the recipient was essentially the same. At this age, I would think that five years would make a good deal of difference. Two questions about that. Any ideas why the younger group tended to use the day care more than the older group? And, second, I don't think this would impact the results of your study -- there's no question that would reduce stress, and so on -- but might this also be a factor related to the difference in the stress of the two groups? That you had a younger caregiver taking care of a given person versus an older person.

DR. ZARIT: I think that's a very good question. We adjusted for age statistically, so any effects due to the age difference in response to day care or not being in day care was taken out before we presented the results. And the means you saw reflected removing any effect that was due to age. I think the reason the day care group diverged in age a bit is that the people who

tended to keep a relative, usually a parent, in day care longer were the employed caregivers who tended to be younger. They used day care earlier in their relatives disease process, and they were more committed to it. They're getting five days a week of help, and they tended to stay in day care longer. Spouse caregivers, someone taking care of a husband or wife, tends to use day care later in the Alzheimer's process. It's a harder decision for spouse caregivers, and they tend to use day care for a shorter period of time. It's more like the last gasp that I was talking about.

ASSEMBLYMAN THOMPSON: Thank you.

ASSEMBLYWOMAN MURPHY: Excuse me, Dr. Zarit. Were these adult day services all Alzheimer adult day care services, or were they a mixed?

DR. ZARIT: They were mostly mixed. Some of the larger programs had a specific Alzheimer program embedded within them, but I think most of them were mixed, and they included Alzheimer patients with other clients in a variety of their programming.

ASSEMBLYWOMAN MURPHY: Thank you very much, Doctor.  
Yes, Joanne.

DR. ROBINSON: Were there restrictions on patient participation in the day care program? In other words, were they limited to patients who were mobile and continent, that sort of thing?

DR. ZARIT: Clients in the day care needed to be mobile. Most of the day cares we worked with did not have continence as a requirement.

ASSEMBLYWOMAN MURPHY: Yes, Renee.

MS. MICHELSEN: Very brief. Did you look primarily at medical day care centers or social or was it not distinguished?

DR. ZARIT: We identified whether they were medical or social programs. About half were medical and half were social. We looked at whether caregivers in one type of program benefitted more than caregivers in another and found no difference.

MS. MICHELSEN: No difference.

DR. ZARIT: The benefits were equal in both types of programs. Now, that's to the caregiver. One might make a case that the benefits to the patient might be a little different.

MS. MICHELSEN: Okay. Thank you.

ASSEMBLYWOMAN MURPHY: Dr. Zarit, thank you very much, and we appreciate your coming in. If there are statistics that you feel we would benefit from and some of those that you used today, a copy would be very gratefully received, and we will distribute them.

DR. ZARIT: I'll see that you get that, yes.

ASSEMBLYWOMAN MURPHY: Thank you very much, Dr. Zarit.

Carol -- is it Levine or Levine? (indicates pronunciation)

MS. LEVINE: Levine.

ASSEMBLYWOMAN MURPHY: Carol, thank you very much for coming today. Carol is the Director of Families and Health Care Project of the United Hospital Fund.

MS. LEVINE: Good morning. I had some slides. Are they available? If we don't have them, we can go it up there. I can't control this

from here? (indicates slide projector) It would be easier if I could. Okay, perhaps you could just follow me.

Again, I'm Carol Levine, Director of the Families and Health Care Project at the United Hospital Fund in New York City. Since its founding in 1879, the United Hospital Fund has been devoted to shaping positive change in health-care delivery and financing. And the Fund works primarily through philanthropy, research, and program and educational development.

I'm very pleased to be part of the panel speaking to you today, and I'm very pleased that New Jersey is taking such an active role in looking at elder care and, specifically, at caregivers. I want to present to you today some findings that we have from a new report called *Rough Crossings: Family Caregivers' Odysseys through the Health Care System*. The report is based on three sorts of information. It's based on a review of the literature about transitions in caregiving, which often accompany transitions in the patients disease course; and a series of six focus groups that we held in New York City; and a series of 28 hospital applications to the Fund for funding for planning around family caregiving.

So if we could have the first slide. (begin slide presentation)

Just a little bit about the focus group participants. There were 55 caregivers. They had to go through a fairly extensive screening to be involved. They had to have had extensive hands-on caregiving experience. They had to have gone through at least two transitions -- that meant taking the patient home from the hospital or bringing them to a hospital nursing home or rehab, so these are experienced caregivers, and typically 44 women and 11 men, a

mixed background in ethnicity, and I would say a very panorama of New York accents in our focus groups. It was a real cross section.

Next, please. The caregivers were pretty much balanced between those who had college education, no college, who were primarily in the low- or moderate-income range. They ranged in age from 20 to 70. The care recipients were primarily older. They were 80 or older -- were 20 of them. Sixty to seventy-nine -- were 25. So this was an elder population primarily.

There was a whole range of relationships. Mothers and grandmothers were the primary care recipients, and aunts. But then there were all other sorts of relationships, and these were the primary care recipients. Many of the caregivers had cared for more than one person in their caregiving career, but we asked them to talk primarily about the one that they were caring for or had cared for. In two groups, the care recipient had died. But you can see the strength of the American family. People are taking care of each other.

These were primarily quite sick people. They had cancer, heart conditions, Alzheimer's, a whole sort of other diseases, and most of them had more than one thing wrong with them. So these were people with very serious and chronic illnesses.

Okay, the main themes in the report describes the lack of preparation that caregivers experienced, the anxiety about taking care of their loved one, and the isolation that comes with long-term caregiving. The transitions were particularly difficult for caregivers because there are times of discontinuity and uncertainty. And during transitions, caregivers often feel a heightened, even overwhelming sense of personal responsibility for the

patient's health and well-being. Caregivers felt unprepared both technically and emotionally for the responsibilities expected them.

I'd like to just give you two quotes from the caregivers themselves. This is a husband whose 71-year-old wife has multiple sclerosis and who had extensive surgery for a very serious bone operation. She was hospitalized for six weeks or so. And he says, "The first night she came home from the hospital, we went to bed, and I found that she was incontinent and that her bandages were oozing. No one had told me what to expect. I didn't know who to be angry at or who to call to help me take care of her."

Could I get some water, please?

The second is a wife whose elderly husband has had several strokes. And she said in a very dramatic way-- She had to take her husband home with a feeding tube. She said, "I was terrified. I don't know about computers. They put in a feeding tube, and they showed me one, two, three, how to use it, but I was expected to be responsible for it at home." And this woman in her late 50s herself was expected to monitor this machine.

Here's another voice which was not in the focus groups. "I had to fight through layers of bureaucracy for 10 days to get a dangerously unstable hospital bed replaced at home. Then when the bed arrived without notice in the evening, when there was no one there to help me move him, it turned out to be the wrong bed." That's a wife who takes care of her 70-year-old husband, who was left quadriplegic and brain damaged after an automobile accident nine years ago. Now, that last voice is mine. Like the caregivers in our focus groups and like Suzanne, I'm one of the more than 22 million or 25 million other caregivers who are struggling with the fragmented, inflexible, and increasingly

complicated collection of institutions and agencies we call the health-care system.

I've had a long career in health policy and medical ethics. I used to come down here to Trenton to talk the Commissioner about AIDS policy years ago. Nothing in my professional life or my experience as a mother of three children had prepared me to be the caregiver for a severely disabled, brain-injured husband.

Now, I just want to quickly go through the themes from our focus groups, and I think we can go on to the next. Caregivers were usually thrust into their role by necessity; although, most wanted to provide care because the ill person was significant in their lives. Caregivers whose family members and friends shared the burden of caregiving fared better than those who provided care alone. I think we've heard that today, and that definitely was in our focus groups.

Next, please. Caregivers' emotional attachment to their loved one was a powerful motive for providing care, but it also led to anxiety and fear about the patient's welfare.

Transitions can be traumatic because there are oftentimes, when caregivers first become aware of changes or deterioration in the patient's condition -- you first have to come to the realization that this person is not going to get better or this is going to be a long, drawn-out thing. And it's a very difficult time. Many caregivers spoke about their sadness, the loss or change in the relationship with the care recipient. Some of the most poignant quotes were, "She's not my mother anymore. I still take care of her and love her, but the person she was isn't there." And that's a very profound loss.

Caregivers experienced discharge from the hospital as an abrupt, upsetting event because the hospital staff failed to prepare them technically and emotionally for changes in the patient's condition. Also, we thought that going home would be traumatic, which it was, but we also weren't prepared for the extent to which the focus group participants found going into a hospital, going into a nursing home, or rehab center, also, very, very traumatic. Many caregivers fear that their loved one will be neglected in hospitals and, especially, in nursing homes. So that means extra vigilance. They have to be there all the time.

In general, participants reported that the hospital staff failed to acknowledge their emotional needs. Not one of the people said that a health-care professional had referred them to community-based agencies for emotional or other kinds of support. Now, that does not mean that they didn't get some information. It just meant that it came at a time when they were too overwhelmed with the responsibility of providing the care to even think about themselves. It's very hard to think about yourself when the person you love is in such bad shape.

Caregivers -- next one. This I think is particularly important for this group. Many caregivers believe that the older people are not treated sensitively in hospitals. There were incidents described-- They were idiosyncratic, but there is a fear on the part of caregivers that older people are -- because they aren't articulate, because sometimes they can't remember things that they will be neglected. Many caregivers want compassion and some understanding from the staff, and unfortunately, many of them don't get it.  
(end slide presentation)

I think I'll stop-- There are many other themes, but most of them have to do with the lack of support that they feel and the lack of training. The moderator asked about religion. Many people brought this up on their own. They were quite philosophical, quite -- looking for answers to their situation, but none of them reported that they found help or solace from a religious organization or their own community. They had spiritual help, but that was mostly their inner faith, not anything that came from an organized religious organization. So there's a, I think, very big role for religions to play.

One thing I wanted to point out is that we're called informal caregivers to distinguish us from the paid workers. But there's something about informal that I don't like. It implies that there is something casual, nonessential about our care. It's informal -- that's sort of fun, not something you have to do. And, essentially, we are the bedrock of the system. So it's very essential. And you've heard about the new kinds of technologies that have to be supported at home. And I think that most of what we've had before has been-- It's important. I don't want to denigrate it, but helping caregivers cope I think that that's important. Coping is good, but I think it's the system that has to change. Part of the stress comes from dealing with the illness, dealing with the tasks, dealing with the change in relationships, but a very huge part of the stress comes from dealing with the system. The system is not responsive to the needs of caregivers.

How can we change? United Hospital Fund has embarked on several initiatives, and I think it's significant that this is an organization which has mainly dealt with hospitals and now it is dealing with family members who are providing care in the community. We commissioned Peter Arno to develop

a systematic estimate of the economic value of informal caregiving in the United States, and he is going to present his estimates for New Jersey to you today. We prepared a series of guiding principles -- Gail mentioned those -- to promote effective partnerships between health-care professionals and family caregivers.

We've embarked on an ambitious three-year, \$1.3 million grant initiative to change the way hospitals work with family caregivers and other health-care providers. We've awarded 16 planning grants to New York City hospitals to gather and analyze information about family caregivers. In February, we will award probably six two-year grants of \$150,000 to \$200,000 to test model interventions. And those programs have to involve family caregivers, and they have to involve a community-based agency. And we hope to work collaboratively with the other organizations you have heard today.

Of course, we can't do this alone. There are a few recommendations that I'd like to suggest to you. First of all, hospital staff should make discharge planning and transitions between home and hospital a process, not a last-minute, one-time event. If there was anything that came through clear and strong, it was that. An hour before you're taking your family member home and you get a list of medications and the nurse says, "This is how you work the feeding tube" -- not enough. You need some of that in the hospital. You need follow-up. You need somebody come in your home and see how it works there because the machinery they send you home with is not the machinery they showed you in the hospital. They do it differently. It's all different in your own home. There needs to be follow-up. Discharge planning

has -- maybe it once worked when people got discharged when they were actually well, but not now.

A high priority should be given to developing a broader array of programs that support family caregivers. Certainly, we need information and outreach to let people know what is available, but there are not enough counseling, respite, and support services for the many, many different kinds of caregivers and their special needs. I always look, "Now, could I use that? Could I use that?" I can't. My situation is so complicated and so difficult that very many of the things that other people can use, well, I can't, but somewhere there must be something that I can use.

Health-care professionals have to be assertive advocates for the family caregivers. Often you feel that the hospital medical professionals are not your advocate. They're trying to get you, the family caregiver, to take on more than you feel you can do because that's the only way to get the person out of the hospital or whatever.

Insurers and their subcontractors should be held to a high level of accountability. In a hospital, my husband's unsafe bed would have been replaced immediately, if for no other reason than concern about liability, but I have no clout as an individual consumer. I think we need a way for consumers to be able to report poor service that they get through the vendors that they use.

Finally, let me say, what can policy makers do? I think you're doing-- What you're doing right now is the most important thing -- is bringing this to the attention of your colleagues, and to propose innovative and leadership programs is an explicit recognition of the critical role we play. And

this implies a recognition of the links between the public sector and the private sector and I, too, am all-- I know that most of the studies are on Medicaid or sometimes on Medicare, but there's a whole vast array of us out there who are in the middle class who aren't in that category. And what the public sector does affects the private sector labor market, cost of equipment -- all of those things are determined by the big bears, and then the little bears, like me, have to try to work with that. So what you do in the public sector affects us all.

I think that health and social policy decision making should include a family focus, like a family impact statement. If you have a regulation, what is the impact on the family?

And finally, I think policy makers at all levels have been ambivalent about family caregivers. I know we're important. They certainly want us to continue doing what we do because, if we don't, that will add to the public burden. But then there's this woodwork effect that everybody talks about: we don't want to do too much because all of these people will come out of the woodwork. Well, it's a very unsettling image for me because what do you think comes out of the woodwork? It's not something very nice -- some pest. Family caregivers are not pests. They need help, and they're the foundation, not just the woodwork. And if they collapse, the whole thing is going to fall down.

Frankly, and finally, family caregivers have very modest requests. They want someone to talk to. They want someone to tell them how to do their job better. They want somebody to recognize that they're not only -- need technical training, but they need emotional support. They want a day off. They want a kind word. These are very modest requests, and I think there

would be a strong -- meeting those requests would be a strong way to humanizing our health-care system for all those involved.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you, Ms. Levine. We appreciate your being here, Carol. Thank you.

Are there questions? (no response)

MS. LEVINE: No questions?

ASSEMBLYWOMAN MURPHY: Thank you again. I think we're beginning to get the message probably, what that means. Thank you very much for taking the time and bringing your expertise to us.

Peter Arno, Ph.D., who was referred to, as part of the Department of Epidemiology and Social Medicine at Montefiore Medical Center at Albert Einstein College of Medicine, economic value of caregivers in New Jersey.

Dr. Arno.

**P E T E R S. A R N O, Ph.D.:** Good morning, almost this afternoon.

ASSEMBLYWOMAN MURPHY: Good morning, yes.

DR. ARNO: My name is Peter Arno. I'm a health economist professor in the Department of Epidemiology and Social Medicine at Montefiore Medical Center in the Bronx. The work that I'm going to present to you this morning is based largely on recent work done with Carol Levine, who you just heard from, the Director of the Families and Health Care Project of the United Hospital Fund of New York.

Over the past few weeks with the help of my colleague, Maggie Memmott, from Montefiore Medical Center, we've generated some new estimates of the magnitude and economic value of informal caregiving in the

State of New Jersey. As I'm sure that most people here are aware of the fact that in 1996, we surpassed the \$1 trillion mark in health-care spending in the United States. And earlier this week, the Health Care Financing Administration announced that in 1997 health-care spending rose by one of the slowest rates in decades -- a mere \$50 billion.

Because of the vast scope of health care and its political, as well as personal, importance, more intense scrutiny has probably been devoted to this sector of the economy than any other. Yet a vital dimension of this far-reaching enterprise has never been calculated in economic terms. And this is the contribution made by unpaid family members and friends who care for the ill or disabled persons, especially in the cases of chronic or terminal illness or serious disability. To fill this gap, we've engaged in a study, which I will describe, which estimates the economic value of informal, unpaid caregiving. But before I do, I'd just like to say a few words of why we did this study.

Firstly, informal caregiving is generally not acknowledged to be of economic value in part because the burden is borne mainly by family members and friends outside the market economy. Personal bonds and familial obligations lead people to become and remain caregivers, despite the sacrifices they have to make. The costs and the value provided, thus, remain socially invisible. Imputing a value to the extraordinary level of caregiving described here may be novel, but it provides a tangible and crucial measure of the massive and vulnerable base on which America's chronic health-care system rests.

In the current economic environment, government programs, private insurers, managed care organizations, and other payers are trying to

reduce formal, paid services. Cost cutting in many instances really leads to cost shifting, adding to the responsibilities of individuals and families. Fewer hospitalizations, shorter lengths of stay, and high-tech medical procedures done at home are only the most obvious manifestation of this trend.

Clearly, some aspects of families' contributions to patient care are impossible to measure such as the comfort of the patient cared for by intimates rather than strangers or the value of care provided at home rather than in a hospital or nursing home. However, other aspects of caregiving can be expressed quantitatively, which I will now describe.

The major question we faced in this study was, what is the annual dollar value of the unpaid family caregiving? In other words, what would this care cost if it were treated as employment paid for by health and social service programs? In order to answer this question reliably, two key questions were analyzed with information that comes largely from large national data sets. The first question is, what is the prevalence of informal caregiving? How much of it is there? And, secondly, what is a reasonable market wage that would have to be paid to replace informal caregiving?

(begin slide presentation) In Figure 1 in the first slide, there are two sets of estimates here of the number of caregivers and care recipients in the State of New Jersey for 1996. On the left side, we have recent estimates on the number of persons with serious disabilities who are recipients of caregiving ranging from 279,000 persons measured by the SIPP, which is the Survey of Income and Program Participation, and 328,000 based on the National Survey of Families and Households. These two large national probability samples from which we extrapolated the data, on the right-hand side -- we have two

separate estimates of the number of caregivers in the State of New Jersey ranging from 712,000 to 837,000 caregivers here in New Jersey. Thus, the midrange estimate would be 775,000, or a little more than three-quarters of a million, caregivers here in New Jersey in 1996. Because the estimate of caregiving prevalence is crucial for this study, I would like to say a few words in how we came up with these numbers.

Can we have the next slide? The data here is based on the National Survey of Families and Households. This national probability sample was conducted in 1987-'88 and asked, specifically, about the number of persons who were caregivers. By making a reasonable assumption that the proportion of caregiving in the population by gender was the same in 1996 as it was in 1987-'88, we can derive reasonable estimates for the number of caregivers in 1996. We then applied these proportions to the number of men and women in New Jersey aged 20 to 94 in 1996, and this gave us our upward-bound estimate of 837,000 caregivers in 1996, which you can see in the lower, right-hand corner of the slide in yellow.

Next slide, please. This figure illustrates a similar approach to estimating the number of caregivers based on an entirely different data set, the Survey of Income and Program Participation, known as the SIPP. The SIPP, also a national probability sample, asked about the number of persons providing informal caregiving services in 1986 by the age of the caregiver. Again here, if you make a reasonable assumption that the ratio of caregivers to each age-group in the population was roughly the same in 1996 as in '86 and that these ratios also hold for New Jersey, then the number of estimated caregivers for New Jersey based on the SIPP would be 712,000. And this

provided our lower-based estimate. And this figure is again in the lower right corner.

Our second task was to determine the number of hours of weekly care -- if we can have the next slide -- provided by informal caregivers. And here again we looked at a number of different studies, but these were mostly small studies of specific diseases such Alzheimer's or Parkinson's disease. And we found that the best estimate was found in the 1996 National Family Caregiving Survey conducted by the National Alliance for Caregiving and the American Association of Retired Persons. This survey found that on average -- on average -- caregivers provided 17.9 hours of caregiving per week. As you can see by the distribution, there's -- close to half of the 46 percent of caregivers provide less than 8 hours a week. And then there's a huge distribution of more than 40 hours a week. But on average and in terms of the economic analysis that I'm talking about, the average is really the key finding.

So if we could have the next slide. The final task then was to determine what would be the appropriate wage rate that would have to be paid to replace informal caregiving. And again, to be as conservative as possible, we used the lowest legal wage rate, the minimum wage, which is currently \$5.15 an hour. And for our upper-bound estimate, we used the national wage rate for home health aides, which is \$11.20 an hour according to the Bureau of Labor Statistics. Averaging these rates together, our midrange estimate is \$8.18 an hour. In this figure, we applied those three different wage rates to our estimates of the number of caregivers, so we have a lower, middle, and upper range. And we applied 17.9 hours per week in all of them, and as you can see in the slide, the economic value of informal caregiving for New Jersey

in 1996 ranged from \$3.4 billion to \$8.7 billion per year, with our best, midrange value at \$5.9 billion per year. From another perspective, these figures suggest that the average care recipient receives informal caregiving services worth approximately \$20,000 per year.

In this final slide, we tried to put our best range estimate of economic value of caregiving into some perspective. This figure represents national data only, but the relationship between spending in each of these categories should be reasonably similar for New Jersey as well. For the nation as a whole, \$194 billion represented our best estimate for the value of informal caregiving across the country in 1996. And as you can see, this figure dwarfs the \$30 billion in paid home care and is about 2.5 times as large as the \$79 billion that was paid for nursing home care.

So in conclusion, let me say that families have been undervalued as contributors to the health-care economy for many reasons. They do not see themselves primarily as caregivers, but as parents, spouses, partners, daughters, or sons. They do not expect to be paid for their work, which they provide out of love, duty, obligation, or lack of alternatives.

Focusing on the economic value of caregiving, especially in a market-driven health-care system, we hope will raise professional and policy makers' awareness of the importance of family caregiving to the smooth functioning of the system, especially as more care moves from hospitals and institutions to homes and communities. Political pressures are mounting to curb the growth of formal, paid home health-care expenditures, which have grown dramatically in recent years. Between 1990 and 1996, total home care expenditures rose more than three times faster than hospital or physician

services, for example. However, efforts to constrain home care expenditures can only exacerbate the burden already felt among informal caregivers. We should be seeking ways to support and strengthen informal caregivers rather than adding new and overwhelming responsibilities to the burdens that they have already assumed.

And lastly, I'd like to commend the Governor for establishing the New Jersey Advisory Council on Elder Care and the willingness of the Council to open up the public discourse on this vulnerable and neglected pillar of our chronic health-care system. By taking leadership on this issue, the Council can help to reframe the issue of family caregiving, which has generally been understood only at the microlevel, where individual caregivers attempt to cope with the stresses and responsibilities of caregiving, to the macrolevel of the health-care system itself, which must find effective and meaningful ways to support and sustain the family caregivers in our country.

Thank you.

ASSEMBLYWOMAN MURPHY: Dr. Arno, do you have copies of the--

DR. ARNO: Yes, I will provide you with a complete copy of -- and the slides.

ASSEMBLYWOMAN MURPHY: Thank you. There is, of course, and always will be, in listening to the caregivers this morning-- You're right, there isn't a dollar value that can be put upon the kind of care that they have given to the people to whom they have given it, nor would those people exchange the money for the person any day of the week. But you're correct in saying that there is a need to draw attention to the kinds of economic benefits

that are accrued across the board by having that home caregiver, and the support needs to be there for those people. The commitment has got to be there for them.

Senator Singer was just outlining some things to me. I'm less attuned to some of this than he is, and I appreciate and hope you'll forgive it.

DR. ARNO: Well, just to put it in a slightly different way. I agree with you. If there was-- In that last slide of the national -- where we compared the value by informal caregivers to the national health-care economy, the informal caregiving component, \$194 billion out of a trillion dollar system, is roughly almost 20 percent of the total health-care system. If there was any other component of our health-care system, be it the hospital sector, physician sector, nursing home, that accrued that magnitude of value, we would be paying a heck of a lot more attention to it than we do to informal caregiving, which is just beginning to -- and barely beginning to be on the radar scopes of policy makers around the country. That's the real reason we painted the economic picture.

ASSEMBLYWOMAN MURPHY: I appreciate that.

Senator.

SENATOR SINGER: Did you take a look at, for example, where the predominant amount of caregivers would be in New Jersey? In other words, is it crowded more to the northern corridors?

DR. ARNO: No. I had no-- No. I don't have any data on that.

SENATOR SINGER: What about economic? In other words, do you tend to find that the caregiver is of low to moderate income, or was there any data available?

DR. ARNO: There's no data. Basically, I presented a model, and that model is based really not on actual caregivers in New Jersey, but modeled based on large national data sets. But the studies out there do suggest it cuts across the board the economic spectrum in terms of who does caregiving.

SENATOR SINGER: Thank you.

ASSEMBLYWOMAN MURPHY: Yes.

DR. ROBINSON: I just have one question.

Peter, did you say how you're defining informal caregiving? Was it just the hands-on people or people who provide instrumental--

DR. ARNO: The definition for the caregiving were the definitions used -- explicitly used in the two large national data sets that we drew from the SIPP and the National Survey of Families and Households. And they were fairly loose -- a little looser than is found in some of the literature in this area, which, unfortunately, up until now has been largely derived from the national long-term care survey, which has kind of been the gold standard out there in the research community and even in Washington and policy-making circles.

The problem with that survey is that it's really a skewed sample of over 65 Medicare only. And those people are sicker than the recipients of caregiving nationwide. In fact, it's not all the elderly that are care recipients or caregivers for that matter. While it's much, much higher as you go up in age, there's clearly a lot of caregiving going on-- In fact, it's almost half nationwide of caregiving is to those under the age of 65. So it really-- It's just one of those stereotypes that's been created that need to be broken a little to really understand the magnitude of caregiving going on.

DR. ROBINSON: Do you have a sense whether if they just try to capture people who were providing hands-on care only or assistance with shopping, and so forth?

DR. ARNO: Oh, no. The data is very clear. The care recipient side particularly are those persons with more than one activity or daily-living limitation, and there are people who are not ill or sick for a day or two, but have to be expected to be ill or have been ill for at least a couple of months. So it is really getting at the chronically ill.

DR. ROBINSON: All right. And so your estimate would be conservative. It really doesn't--

DR. ARNO: Absolutely.

DR. ROBINSON: Right.

DR. ARNO: I mean, the numbers are so huge that in every turn in this analysis we went the most conservative way as we could, using the minimum wage, for example, or using 17.9 hours per week as an estimate for the number of caregiving hours, which is in many-- In every study we looked at, it was the lowest number we could find. So we try to be conservative because the numbers are so large anyway that we want to maintain as much creditability and not have anybody nickel and dime us on silly little things, when the value is huge to begin with.

DR. ROBINSON: Thanks.

MS. MICHELSEN: Excuse me, Madam Chairperson, may I just clarify our mission?

ASSEMBLYWOMAN MURPHY: Yes.

MS. MICHELSEN: Our mission is the elderly group. This is the Elder Care Task Force. So we are looking, not at the general disabled community, but 60 and over. Okay, thank you.

ASSEMBLYWOMAN MURPHY: This is what this group-- But clearly, anything we learn and benefit from in this group is--

MS. MICHELSEN: Absolutely. I just don't want the issues of multiple different groups to be confused here.

ASSEMBLYWOMAN MURPHY: Appreciate it.

DR. ARNO: I just say it's a wider issue than the elderly.

MS. MICHELSEN: Right.

DR. ARNO: But when you look in the age groups over 65, the problems of caregiving goes up dramatically. There's no question about it.

ASSEMBLYWOMAN MURPHY: Are there other questions for Dr. Arno? (no response)

I appreciate your coming today, Dr. Arno, and we will appreciate your statistics. I think, as we get further into this, everything we have heard today will begin to form more of a solid background for people like myself, who are fairly new into this. For some of the professionals who are here, clearly, they are with you, if you will, in the comprehension level. This is a real eye-opener. I thank you very much, Dr. Arno.

DR. ARNO: Thank you.

ASSEMBLYWOMAN MURPHY: Susan Friedman, who is the Executive Director of The Grotta Foundation -- role of philanthropy and the clergy. Certainly we have heard a little bit on one side of that.

I'm looking forward to hearing you this morning, Susan.

**S U S A N R. F R I E D M A N:** Thank you. Good morning or good afternoon. It was supposed to be morning.

Again my name is Susan Friedman. I'm the Executive Director of The Grotta Foundation for Senior Care of South Orange, New Jersey. The Foundation was created in 1993 from the sale of The Grotta Center for Senior Care, which was a nursing home and rehab center, and as the law requires, when a nonprofit facility is sold, the proceeds must go into a philanthropy. To be constant with our mission, our focus for the past five years has been to support services for the elderly of New Jersey and their families.

And we also want to commend Governor Whitman for creating this Council and thank the Council providing this forum and inviting us to come to talk about the irreplaceable roles of caregivers. And, parenthetically, I should note that I've made a similar presentation to the U.S. Select Committee on Aging, the Senate Committee on Aging in Washington in September. And I think we had two, maybe three, Senators that actually showed up. So I'm very impressed that so many of you are here. And that's half the game -- is showing up anyway.

In 1997, through a process of community needs assessment and strategic planning, the Foundation chose caregiving -- family caregiving of the elderly as our major priority. This was not only because of the emerging demographics that you've heard about, so I'm not going to repeat them, but also it was an issue that deeply resonated from my board on a personal level. Because I think we all realized that we all either are, will be, or have been caregivers in some point in our lives.

In creating our agenda-- We are a small foundation. We have assets of about \$10 million, and we give out about a half million of that a year. We decided to look at what other people were doing because we are very happy to replicate other good ideas. And what we found is that caregiving has not yet taken a major place in philanthropic agendas. There are certain notable exceptions. I'll just briefly mention them. You might want to look into what these folks have done. The Archstone Foundation in California. The Brookdale Foundation of New York, with whom we partner, are in 30 states currently for their National Alzheimer's Respite Initiative. We've brought that to New Jersey as of two years ago. You've heard about the United Hospital Fund, of course, and New Jersey's own Robert Wood Johnson Foundation with Faith in Action. I don't see them here today, but they're a major player. I know this list is not all conclusive and inclusive, but when you consider the thousands and thousands of foundations that are in this country, it's a rather small list.

So we looked further into the corporate arena, and as I think was mentioned here, the corporate response to caregiving really had to do with employee productivity in the early days in the '80s. How to keep the employee on the job and, therefore, offer this as an employee benefit. More recently, there have been a couple of corporations, like Equitable, that works with the National Alliance of Caregiving -- I saw Gail Hunt back there. And Pfizer, that's worked with the National Council on Aging on a program called Innovations for Independent Living that's focused on caregiving this year and have done this as a community service. But for the most part, this has been an issue of economics.

So without too many role models, we've decided to take a broad-brush approach to caregiving and find a whole range of caregiving programs, and we're currently supporting 18 caregiving programs, mostly at the local, State, and one or two at the national level. What have we learned from these programs? Let me share with you some of our programmatic experiences. You've heard a lot of statistics and a lot of trends, but now I'm going to get down to programs here in New Jersey.

First thing we learned that caregivers -- and I'm sure that everyone knows this, but I'm just going to mention it in any event. Most caregivers don't work for corporations. They are not the adult child -- the employed child of an older person that many corporations focus on. This certainly, about 50 percent-- But I think Dr. Zarit pointed out 45 percent are spouses, who have impairments of their own. What impact is there on a marriage when one member of a marital relationship becomes the caregiver? You've heard from caregivers, so you see there's certainly an impact.

We've given a grant to Mainstream Counseling Center of West Orange, New Jersey, and they developed a special outreach to spousal caregivers, and they've created a marital counseling program for caregiving couples.

You'll have to excuse me. I have a cold, so I'm going to have to blow my nose in a minute.

And they're also doing group interventions with caregivers, not support groups, but actually group therapy with caregiver couples to try to strengthen that role to maintain the marriage relationship in the face of the changing roles of the caregiver relationship.

Caregivers we've had also are grandparents. Today, particularly in urban centers, but I think everywhere, the pandemics of AIDS and drugs have orphaned literally millions of children in this world and even in this country. What happens when those grandparents who step in to care for those grandchildren, which is what's happening, are also caring for an older mother or father or an aging spouse?

We've given two grants, one to Capital of Passaic-- I don't know where all of you Assembly and Senator folks are from, but if you are from the areas where there programs are and want to talk to me after the session more specifically about what the programs are doing, I'd be happy to do it. But I'll just mention, also, the Grant Families Program in Montclair, the Salvation Army, that we fund, which looks at this really beleaguered group of grandparents, who usually are women in their 50s, 60s, and above, caring for children who are young to teens and having an 80, 90, or even beyond parent to deal with or a spouse. So it's a really difficult situation, and these programs are looking at what their needs are.

Another emerging demographic is the aging of the developmentally disabled population. I know this focus is aging, but in truth, those folks who are suffering from what is called developmental disabilities, substantial neurological problems, etc., are now living into their 50s and 60s. Their caregivers are people who are in their 70s, 80s, and 90s. And the issue of who is going to take care of my child when I die, which all parents think about a little bit, becomes very urgent and poignant for these people.

This is really an opportunity that I see for the aging service network to combine in advocacy -- and I see Commissioner Fishman is not

here, but tell him I said this -- with the developmental disabilities community. And that has begun actually -- those discussions, I know. We funded a group called JESPY House in South Orange and Arc of Union County, and they're both taking two different approaches to working with these populations. One is educational, working with the population of people in their 40s and early 50s -- the JESPY House -- who will have to learn about the processes of aging that no one ever thought to teach them before and, also, the issue what happens when mom or dad dies before them. And at Arc of Union County, they are starting a planning process and getting together a voluntary advisory board of accountants and bankers and financial planners who will work with these parents, particularly those who don't have economic resources, to buy into some of the annuities that are around to help them plan for their futures.

What do caregivers need? Well, again, programmatically what we see that they need is respite. We've heard all about that in every permutation, and we believe that adult day care, particularly social adult day care, from our perspective, is at the cornerstone of that. We've, as I said, have a partnership with the Brookdale Foundation in New York. And we also have -- I'll bring Dr. Zarit's attention to -- a program, which is in Montclair, called Senior Care and Activity Center, what's called the Club. It is for first-stage Alzheimer's victims, at the very beginning of the disease, and for their caregivers. It is to-- It has been an extensive outreach for the medical professions in that community to identify as they have been diagnosed to bring their families into the Center for this two-day-a-week program and to begin to work at crisis intervention and making that into a one-stop center for services, for information, and respite and referral.

You've heard caregiving is a 24-hour commitment, and we agree. We have given a grant to Muhlenberg Adult Day Care Center to enable them to provide a couple hours a month, unfortunately that's it for the moment, of evening care so that the caregivers who have connected to this day center can attend support groups. They were not attending the support groups because they didn't know who and how to leave the people who were in their care. They didn't feel it was safe. So now they can bring them to the Center, and activities are planned and appropriate staff are there for the individual victim, in this case, of Alzheimer's disease, while the caregiver can take part in these programming.

I think the next logical step-- We're not funding it, but I'd like to fund something like this, which is overnight respite care. I know the Hebrew Home and Hospital of Riverdale has a program where once or twice or a couple times a month a caregiver can bring their Alzheimer's victim in the middle stages, when the disease very often results in day and night being about the same thing for the victim, and they can leave the patient there with staff for the night. They can go home and get a good night's sleep. Staff works with them. There's programming. And in the morning, they can come pick up their family member and continue their caregiving role throughout the day.

My own mother-in-law was a victim of Alzheimer's disease, and I recall my father-in-law's exhaustion because she just stopped sleeping at night and catnapped throughout the day. And it was really very exhausting for him. This, I believe, would really address that for people and give them a certain measure of relief.

We believe that the nation needs to rethink its commitment to adult day services and make it an affordable option for the average American. In 1996, we joined five corporate funders to fund the National Council on Aging. They put together a blue-ribbon task force to develop universal standards for day care. Well, they're out there now, since 1997. It's been published. We'd like to see government use it. We'd like to see managed care use it. It shouldn't only be government. Management care industry, we believe, should have an investment in this.

For many caregivers however, care begins or remains at home. Day care is not an opportunity, and the availability of quality home care is a linchpin of that home care caregiving plan. We believe that a home care workforce that is sensitized to the needs of caregivers and sees them as part of the planning and treatment team is really critical.

We've given a grant to the Jewish Vocational Services of Metro West, which recruits mature adults, trains them -- many of whom have been caregivers at some point in their life -- trains them as certified home health aides, has a curriculum which focuses on reinforcing the concept of the care partnership between the caregiver and the home care worker. Because often, when a home care worker comes in, there's turf issues -- how to resolve those, and how to make a partnership there.

In addition, we've also looked at how to bring some of creative programming from day centers into the home where people can't, in fact, leave the home. The Alzheimer's Association of Northern New Jersey has had two grants from us. One for something called At Home with the ARTS. ARTS stands for something. I forget what exactly, but it's a 12-week art and music

therapy program. It's designed-- The art and music therapist comes into the home, work with the individual-- There's a great deal of stimulation that goes on that's very important to the maintenance of health. And at the same time, they train the family caregiver to maintain the regimen when the program is over. They continue that connection through materials, written materials, and kind of a help line -- a telephone help line, if a caregiver can't remember how to do a particular technique and maintain the program that way.

The Family Service in Morris County also has a similar concept that we funded. They bring occupational and recreational therapy into the homes of individuals who are mentally intact but physically too frail to leave the home. Again, they do go through a whole series of this training of the caregiver and support after their initial program is over. So we think that has a lot of merit, and they've been going very successfully.

I mentioned, including the caregivers part of the treatment team, we have been working with the New York University Hospital -- their Alzheimer's Disease Center -- to fund a handbook for caregivers. I think one of the statistics, however, was mentioned earlier. I'm sorry I came late, but-- When an individual with dementia is hospitalized, the standard difference in length of care -- and this I'm sure has changed since managed care has come in, but a couple of years ago was 17 days for a frail, older person who has had surgery compared to 36 days of a dementia patient in the same situation. Now, of course, they're trying to get people out a lot faster, but nonetheless, the parallel has got to remain.

This handbook that they're working on and developing through focus groups and forums and meetings, with not only NYU medical staff, but

the medical staff and social service staff of University Hospital of Newark, is to develop this handbook that will help caregivers become active advocates. And I know the United Hospital Fund is working, also, with them on a companion program for the hospital staff, which I think is really important, again to involve the caregivers, a legitimate member of that treatment team.

We've also looked at putting our money into developing new resources to reduce isolation and burden of the caregiver. We think older people themselves are an unplugged resource for that kind of service. We've given another grant to the Alzheimer's Association of Northern New Jersey, and they are now training special companions -- senior companions -- who go into the home where there is a caregiver relationship and work with them on the care plan that's been developed by their social workers and, as sort of the extension of that plan, I'd also -- just another person to support them emotionally. They don't provide specifically respite; although, they allow for that, also, during those hours.

Another area of opportunity that we think has been overlooked is the wealth of volunteer resources which faith-based communities can offer to enrich the lives of older people. We've just completed the first year and a half of a special initiative, which we call Synagogue HOPE, Help, Opportunities, and Programs for Elders. Our Foundation is nonsectarian, but our roots are really in the Jewish community -- what's called Metro West New Jersey -- and, therefore, we do have some special initiatives for the Jewish community. Through this grant, we're funding pilot programs at local congregations to try to open up whole areas of programming for older adults and for caregivers of older adults. We believe, as a surrogate extended family and mutual support

and an extension of pastoral care, congregations can have a powerful potential to change the lives of caregivers in a positive way, regardless of what denomination they come from.

On October 27, we hosted a conference called “Putting Elders Back on the Congregational Agenda.” I couldn’t carry too much (indicating handouts), but I could pass this around if anyone wants to see it. It looked at the issues and opportunities that I’m just discussing. We had more than 200 people attend, about half from Jewish congregations, the other half from the social service community, to look at how partnerships can be created between the two sectors and what the unique role of the congregations can be in strengthening this continuing care that we all talk about.

At the conference, Dr. Amy Sales from Brandeis University reported on a Grotta-funded national survey that we’ve just completed on synagogue-based programming for older adults, and the findings of the survey have been put into a 150-page book. I couldn’t carry them all, but I’d be happy to send them to any or all of you -- anyone who’s interested. It details 20 models of synagogue-based programming, which are completely replicable to any denomination and any religion, we think, and one of the eight chapters is called “Comparing Caregivers” and highlights five faith-based approaches to addressing the needs of family caregivers.

One model that I’ll just highlight is one that we hope to bring to New Jersey. It’s called As Families Grow Older. And it’s a pilot caregiver education program created by the Winter Park Health Foundation in Florida. It’s being tested there now. It is not new. Caregiver education is not a new concept, but what is new about this is that it is looking at the strengths of

faith-based communities, churches, mosques, synagogues and what they can offer. It's a model which is volunteer driven. It's consortium based, and we're looking to bring it to New Jersey and test it here in Essex, Morris, and Union counties, which are kind of our target area for our little testing programs.

We feel that what you're doing here and what the Senate was trying to do and I'm sure they're beginning to do is a really commendable first step. But we feel that certainly a lot more needs to be done. We've actually joined with a number of other funders to support the National Health Council, and I'm glad to see Myrl is here. Their first Consensus Development Conference on Caregiving, which is in December, and is going to bring together-- I'm sure she'll tell you about it, so I won't tell you any more about it. But we feel that one of the issues for our Foundation -- and we're a conversion Foundation, which means, as I said, we were created from a facility. Our goal initially was to serve Essex, Union, and Morris counties in New Jersey, but what we've learned over time is that, though we do direct a lot of our funding there, in order to make an impact for our communities, we really need to look not only at the local level, but at the State level working with you folks here and, also, at the national level. And so we're very pleased to be part of that.

We believe caregivers are really a national treasure, an overlooked national treasure. Their collective selflessness in providing continuing care for older adults has really spared this country a staggering financial burden, which you've heard about from Peter and others today. Really, without the extraordinary contribution of everyday people, the life in this country would not be what we know it today. I'm just going to quote from my favorite

suffragette, Elizabeth Cady Stanton, who said that the “prosperity of a nation could be judged in the way it treats its elderly.” I’d like to suggest a corollary. That the way we care for those people who take care should also be what marks us for future generations.

Thank you for inviting me, and do you have any questions?

ASSEMBLYWOMAN MURPHY: Thank you, Susan, and thank you. Do you have a copy of the comments that you made today?

MS. FRIEDMAN: Yes. It should be part of your packet.

ASSEMBLYWOMAN MURPHY: You referenced some programs that we might be able to look at and--

MS. FRIEDMAN: And I would be happy to share more information about them.

ASSEMBLYWOMAN MURPHY: --if you could leave a copy of that, why, we will be able to pull them out of it.

Thank you very, very much.

MS. FRIEDMAN: Fine. Okay, thank you.

ASSEMBLYWOMAN MURPHY: Are there questions? (no response)

MS. FRIEDMAN: You’re tired.

ASSEMBLYWOMAN MURPHY: Thank you very much. Thank you for coming.

MS. FRIEDMAN: Thank you.

ASSEMBLYWOMAN MURPHY: Mryl Weinberg, who is President of the National Health Council and her efforts to assist employed

caregivers, and Myrl has made available to all of us a transcript of her remarks. So we appreciate that.

**MYRL WEINBERG:** I want to, obviously, thank you very much for the opportunity to testify today and commend you for the amount of time and energy you are devoting to these important issues. I also feel like at this point I should commend you for your stamina. I know it's been a long morning.

To put my testimony in context, I wanted to just take a moment to tell you a little bit about the National Health Council. The Council is a private, nonprofit umbrella organization for more than 100 health-related organizations. Our core membership are those voluntary health agencies like the American Cancer Society, Alzheimer's Association, Easter Seals Society, and National Multiple Sclerosis Society. We have about 45 of those types of organizations that represent over 100 million people with chronic diseases or disabilities. In addition, we have members such as the National Family Caregivers Association, who you've heard from this morning, American Association of Retired Persons, the American Medical Association, and private businesses such as Pfizer, Amgen, and Aetna U.S. Healthcare.

The Council's mission is to improve the health and well-being of those persons with chronic diseases and/or disabilities.

You've heard today some of the statistics about the increasing need for family caregiving, the projected decrease in the number of caregivers available, the financial contribution caregivers make to our nation's health-care system, and the often overwhelming burdens many caregivers face.

There are many areas where caregivers require support to enable them to provide the best care possible and to maintain their own physical,

emotional, and financial well-being. Today, I have been invited to address caregiving needs in relation to the workplace and the types of policies and practices employers can implement to support caregivers and enhance their productivity as the caregivers strive to meet the needs of both the persons for whom they provide care and their employer.

While working outside the home provides a welcome outlet for many caregivers, they nevertheless face added stress from managing the competing demands of family and employer. Thus, caregiving is a growing component of the work-family equation. In the future, even more employees will be juggling work and family issues as they become caregivers for older persons. As such, the workplace and the relationship between employees and employers form an increasingly important partnership in developing a nationwide agenda for caregivers.

Clearly, there is no single model for supporting the caregiver who works outside the home. Large companies are better suited to establish support and referral programs than are medium and small ones, but steps can and should be taken by companies of all sizes. We have found that the culture and values of each organization or company may be the best predictor of caregiver-friendly workplaces. It is encouraging to note that more than four in five caregivers who work report that their employer's attitude toward the demands of caregiving is understanding, but there is much more to be done.

Employment is a financial necessity for many caregivers. Although some people must quit their jobs when they take on caregiving responsibilities, close to two in three caregivers are working -- 52 percent full-time and 12 percent part-time. One study found that nearly half -- you heard about it

earlier -- of employed caregivers were spending more than 40 hours per week on caregiving activities. And according to the National Alliance for Caregiving, the profile of the typical caregiver today is a 46-year-old woman who is employed and who spends about 18 hours per week caring for her mother who lives nearby.

ASSEMBLYWOMAN MURPHY: Mryl, at the risk at sounding extraordinary rude--

MS. WEINBERG: Yes.

ASSEMBLYWOMAN MURPHY: --since you have given us this in writing--

MS. WEINBERG: Right.

ASSEMBLYWOMAN MURPHY: --which you were reading, are there specifics in here that we should focus on rather than reviewing the entire--

MS. WEINBERG: Absolutely.

ASSEMBLYWOMAN MURPHY: Because we will read it all.

MS. WEINBERG: Sure. What I'd like to then do is go straight to the recommendations--

ASSEMBLYWOMAN MURPHY: Good.

MS. WEINBERG: I don't have mine numbered the same way (indicating written testimony), but it's near the back. I think that I wanted to lead into that and just let you know--

ASSEMBLYWOMAN MURPHY: Your options for action?

MS. WEINBERG: Yes.

ASSEMBLYWOMAN MURPHY: Good.

MS. WEINBERG: And to lead into those options. I wanted to just preface what you will find in the testimony is that the Robert Wood Johnson Last Acts Campaign, which is a nationwide campaign looking at these types of issues, has a workplace task force which the National Health Council chairs, and we are conducting three research projects, in-depth telephone interviews with caregivers of a person who's terminally or who has died in the last two years. That's completed. Focus groups with employed benefits managers in large, medium, and small employers and a mail survey to over 2000 employers. We have developed and will finalize after all this research is done a model activities package for caregivers in the workplace. So we will have that available later.

ASSEMBLYWOMAN MURPHY: Do you have time lines on when those things will be available? Obviously, you have predictable closure dates.

MS. WEINBERG: Right. Before the end of the year.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. WEINBERG: So let me go to some of the options, and actually I was only going to highlight a few of those. So I will cut to the chase here. In highlighting these and looking at all the work that we've done, we believe that employers purchasing group plans, especially large employers, should insist that insurers cover the cost of community- and home-based long-term care.

Laws should be enacted granting tax incentives to employers offering creative services such as on-site day care, payment of care expenses as

part of cafeteria-style benefit plans, programs that link long-distance caregivers to services, and group long-term care insurance.

Employers should implement policies that allow employees to make changes in daily work schedules in order to provide long-term care and to cope with crisis. For example, and these are some of the policies we're finding are very beneficial: flextime, telecommuting, job sharing, and then sick leave banks.

Employers in labor organizations should conduct need surveys to better understand and address the needs of their caregiving employees. Employers should also provide referrals and counseling through employee assistance plans. And very importantly, they should incorporate into supervisor and management training programs instructions on how to accommodate and assist caregivers.

In closing, I just want to take a moment to go back to what Susan from The Grotta Foundation mentioned -- is that we believe at the National Health Council that these issues are so serious that we are holding a Consensus Development Conference on Caregiving in December with several of the organizations that are here today. And the purpose there is to really take all the issues and all of the work that has been done and to move forward so that we will have concrete measurable steps that we believe can be accomplished in the next three to five years, a real action plan to try to resolve some of these caregiving issues on a national basis.

And I do thank you very much.

ASSEMBLYWOMAN MURPHY: Sick leave bank, could you talk a little bit about what that is in practicality?

MS. WEINBERG: Yes. What it means in some organizations is that employees who have sick leave and are not utilizing very much can donate it to a bank so that it then becomes available for persons who have crisis situations, and they can borrow from it without loss of pay.

ASSEMBLYWOMAN MURPHY: Okay.

MS. WEINBERG: Is that clear?

ASSEMBLYWOMAN MURPHY: Yes, it does. It raises a whole lot of pluses and minuses because sick time has in many instances, and particularly in the government system, been something that people bank and retire with -- quite often retire with a year, 300-and-some-odd days, say, of paid time because it was sick leave that they didn't use because they were never ill. Looking at some of these things as different ways of translating the value of sick leave or sick time.

MS. WEINBERG: I might say that in my experience more with certain of the private sectors and especially voluntary health agencies and some other private companies I'm aware of, that would absolutely not be possible to save up sick leave. You lose it at the end of the year.

ASSEMBLYWOMAN MURPHY: That's right.

MS. WEINBERG: And, in fact, the trend is to combine your sick, your vacation, and all leave, and you get so many days -- 14, whatever it is, and that's it. So I almost feel like the trend is tightening up the other way. I worked at the American Diabetes Association for several years, and we had a pool, a bank, of sick leave just for these kinds of circumstances where employees could borrow and have sick leave that someone else had donated.

ASSEMBLYWOMAN MURPHY: I think it's a marvelous--

MS. WEINBERG: So it does work.

ASSEMBLYWOMAN MURPHY: It's a marvelous concept, too.  
Oh, I'm sorry. Assemblyman Romano.

ASSEMBLYMAN ROMANO: Just one quick question. I hear you have creative services such as on-site day care. Now, we haven't heard this before. Are you talking about adult day care, or we talking about children day care?

MS. WEINBERG: We're talking about adult day care.

ASSEMBLYMAN ROMANO: Pardon me?

MS. WEINBERG: Adult day care.

ASSEMBLYMAN ROMANO: I believe you're the first one-- It was in my mind before, but you're the first one who have brought it up about adult day care--

MS. WEINBERG: Right.

ASSEMBLYMAN ROMANO: --at a place of employment.

MS. WEINBERG: That's correct.

ASSEMBLYMAN ROMANO: Thank you.

ASSEMBLYWOMAN MURPHY: Wonderful.

MS. WEINBERG: Thank you. Thank you very much.

ASSEMBLYWOMAN MURPHY: Thank you, and thank you very much for accommodating us.

MS. WEINBERG: You're quite welcome.

ASSEMBLYWOMAN MURPHY: We really appreciate it.

MS. WEINBERG: I certainly understand.

ASSEMBLYWOMAN MURPHY: Ladies and gentlemen: thank you all for being here.

To the members of the Task Force: you have a schedule of our next meetings which will be--

ASSEMBLYMAN ROMANO: Was that it?

ASSEMBLYWOMAN MURPHY: Well, that's it unless there are questions or discussions.

ASSEMBLYMAN ROMANO: No. I mean, is that the end of the testimony?

ASSEMBLYWOMAN MURPHY: That's the end of the testimony this day. Our next meeting will be December 9 from 12:00 to 3:00 at Newark Beth Israel Medical Center. Directions were given to the members. If there are people that you would like to hear testify or members that you want to contact-- Assemblyman Romano has contacted many of the people in the physical area that he is close to.

ASSEMBLYMAN ROMANO: Madam Chair, may I bring up one point, though, while we have all these people here? Are there any materials now about caregivers that would be available to us? I mean, we don't have to wait for a report.

ASSEMBLYWOMAN MURPHY: People are going to submit--

ASSEMBLYMAN ROMANO: Okay.

ASSEMBLYWOMAN MURPHY: --and we will get their comments.

ASSEMBLYMAN ROMANO: I'd like to get some information for my legislative office. I have a repository of all sorts of materials, and there are senior citizens who come in on a regular basis to see what's new.

ASSEMBLYWOMAN MURPHY: Thank you again.

**(MEETING CONCLUDED)**