

---

---

# ***Public Hearing***

before

## NEW JERSEY ADVISORY COUNCIL ON ELDER CARE

*“Testimony concerning health care and caregiving for the elderly”*

---

---

**LOCATION:** Newark Beth Israel Medical Center  
Newark, New Jersey

**DATE:** December 9, 1998  
12:00 p.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  
Vivian E. Greenberg  
John Michael Heath  
Renee W. Michelsen  
Roberto Muniz  
Joanne P. Robinson  
Lennie-Marie P. Tolliver



**ALSO PRESENT:**

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

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

---

---

## TABLE OF CONTENTS

	<b><u>Page</u></b>
Sam Crawford Corporate Director Senior Health Services Saint Barnabas Health Care System	5
Carol Kientz Executive Director Home Health Assembly of New Jersey, Inc.	10
Susan Feder Representing Individual and Family Institute	14
Elio Mancini Private Citizen	17
Loretta Melito Essex County Coordinator New Jersey Statewide Respite Care Program	20
Bev Aubrey Caregiver	22
Stewart Aubrey Alzheimer's Patient	22
Patricia Mahmarian Social Worker and Program Director Alternate Family Care Program Visiting Homemaker Services of Bergen County	24
Maxine Cohen Caregiver	26
Barry L. Moore Private Citizen	29

## TABLE OF CONTENTS (continued)

	<b><u>Page</u></b>
Gretel D. Weiss, Ph.D. Representing Older Women’s League, and Member New Jersey EASE Advisory Committee and Interagency Council on Osteoporosis New Jersey Department of Health and Senior Services	31
Rella DeSimone Caregiver	36
Tracy Baroni Director of Policy Pharmaceutical Research and Manufacturers of America Washington, D.C.	37
Dominic Gangi Caregiver	43
Shirley Howell Caregiver, and Support Group Facilitator Overlook Hospital Alzheimer’s Association	46
Queen Sanders-Phillip Home/Friend Director Orange Senior Services, and Caregiver	48
John Cannon Caregiver, and Member, Board of Directors Northern New Jersey Chapter Alzheimer’s Association	50
Eudie Schachter Support Group Facilitator Alzheimer’s Association	53

## **TABLE OF CONTENTS (continued)**

	<b><u>Page</u></b>
Yvonne Thomas Practical Nurse and Massage Therapist, and Caregiver	54
Jack Becker Caregiver, and Support Group Facilitator Alzheimer's Association	59
Catherine Macchi Office of Senior Affairs Jersey City	63
Miriam Cohen Director of Referral Services Essex Valley Visiting Nurse Association	65
Barbara Havlik Executive Director Life Management, Inc., and Guardian	71
Agnes Coleman Caregiver	75
Joann Rizzo Representing Morris County Senior Service Providers Group	77
Beth Tilkin Social Worker Grenlora Nursing Home	79
Vivian Nichols Caregiver	81

## **TABLE OF CONTENTS (continued)**

	<b><u>Page</u></b>
Lois Corwin Passaic County Home Care Options New Jersey Statewide Respite Care Program, and Representing John Voyce Caregiver	82
Dennis Joy Caregiver	86
 <b>APPENDIX:</b>	
Testimony submitted by Sam Crawford	1x
Testimony submitted by Carol Kientz	5x
Testimony submitted by Elio Mancini	7x
Statement plus charts submitted by Patricia Mahmarian	13x
Testimony submitted by Tracy Baroni	17x
Statement submitted by Miriam Cohen	21x
lmb: 1-88	

**ASSEMBLYWOMAN CAROL J. MURPHY (Chair):** Ladies and gentlemen: I will tell you that we are going to begin the hearing. We have such a number of speakers today. And while we don't have identifying cards and while I don't have a timer, and we don't have place cards in front of us, we will go around the room and introduce ourselves so that you will know in front of whom you will be speaking and to whom you will be testifying as we proceed with this elder care program.

Do you know-- We have a number of speakers today. We have a full, full number. This hearing runs till 3:00. We do have a full hearing. And if possible, we here will try very hard to direct pertinent questions to you, not to engage in statements. Please know we are so encouraging of all of you and so grateful to you for coming today. But in the interest of trying to hear everyone who has come, who has something that they feel they really want to say and put on the record, we're going to try very hard to move the process along. So I will be telling you when your five-minute time period for speaking has come to a close.

Our goals as a Council are to address all economic levels, all types of living arrangements, all kinds of care arrangements, and all of the things that we need to do to make living better. Understanding that science has given us the capability to live for many, many years, the only people that can give us the quality of that life are we ourselves in terms of our preparing ourselves, preparing a system, planning personally, planning as a state, and in supporting one another and in supporting the system. Remembering that from 1960 to 1994, the number of people aged 84 and over increased by 274 percent, amazing, 274 percent. If someone told you you could have a sale and get

something 270 percent off, you'd know they were giving it away. We'd all run. (laughter) And that's compared to 100 percent of growth for the people aged 65 and over, and only 45 percent growth for the total population. So we have just moved ahead by leaps and bounds, and it shows you how well we are. It shows you how much planning we really need to do to be ready for ourselves as we move along.

In July of 1994, there were 33.2 Americans who were age 65 and over, one-eighth of the total population. Isn't that amazing? We all look so wonderful and feel so good. Between 1994 and the year 2020, America's 85-and-older population is projected to double to 7 million people, and it will swell to between 19 million and 27 million people by the year 2050, making these seniors the fastest-growing segment of the population. People aged 85 and older are the heaviest users of long-term care. Nearly one in four lived in a nursing home in 1990, and approximately 1.5 million people live now in our nation's 17,000 nursing homes. So we need to look at other kinds of facilities, other kinds of mechanisms for caring for ourselves and those to come behind us.

Seventy-five percent of these people are women. That's one out of-- For every two men over 85, there are five women. So these men are very valuable. We need to protect them even better. (laughter) There will never be enough to go around. We've got to be very careful of these resources.

We have two more public hearings. We have one in Neptune and one in Vineland. I thank all the members of this Council, who are extraordinary people, and we thank all of you who are here to listen, to learn, and to testify, for giving of your time and of giving of your interest because I

know this is the very busy time of the year. I don't think we ever don't have a time that isn't busy, but this is extraordinary so with the holidays coming. So thank you very much for being here with us today, and we will proceed with the first speaker.

Commissioner Fishman I know will be along shortly, and we will let him speak when he arrives.

Thank you very much.

And the first speaker is-- Oh, the panel is going to introduce themselves. The first speakers can get ready. They are to be Carol Kientz from the Home Health Assembly of New Jersey; Sam Crawford, Saint Barnabas Health Services; Victoria Hassar; Loretta Melito -- are the first four speakers.

And the panelists will introduce themselves beginning on my left with Ruth Reader.

ASSISTANT COMMISSIONER READER: Good afternoon. I'm Ruth Reader. I'm Assistant Commissioner at the Department of Health and Senior Services, the Division of Senior Affairs.

SENATOR ROBERTSON: I'm Senator Norman Robertson. I represent the 34th Legislative District, which encompasses parts of Essex County and Passaic County.

DR. ROBINSON: I'm Joanne Robinson. I'm an assistant professor of nursing at Rutgers University.

MS. MICHELSEN: I'm Renee Michelsen. I represent Atlantic Health System at hospitals in Morris, Essex, and Union counties, and I'm also



the Chairperson of the Morris County Senior Service Providers Group representing the agencies in Morris County serving the aging.

DR. HEATH: I'm John Heath. I'm a physician specializing in geriatric medicine. I direct a geriatric fellowship training program within The University of Medicine and Dentistry of New Jersey.

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

MS. GREENBERG: I'm Vivian Greenberg. I'm a clinical social worker with a private practice in Pennington, New Jersey. Caregiving has been a special interest of mine for over 23 years. I've written books and published books on the subject, and here I am to find out as much as I can from all of you.

DR. TOLLIVER: I'm Lennie-Marie Tolliver, a member of the New Jersey Commission on Aging.

ASSEMBLYWOMAN MURPHY: Lennie also was a commissioner on the Federal level in dealing with the aging population and their needs as they move forward, so we have great expertise.

DR. TOLLIVER: Yes. I was the administrator for the Administration on Aging in Washington for four years.

ASSEMBLYWOMAN MURPHY: Sam.

ASSEMBLYMAN THOMPSON: Assemblyman Sam Thompson from the 13th District, representing a portion of Middlesex and Monmouth County, a member of the Assembly Health Committee.

MS. EDELSTEIN: I'm Theresa Edelstein. I'm the Director of Continuing Care Services at the New Jersey Hospital Association. I'm also a licensed nursing home administrator in New Jersey and New York.

ASSEMBLYMAN ROMANO: I'm Assemblyman Lou Romano from the 33rd Legislative District, which constitutes northeast Hudson County. And for your own information, I may look very well, but I am a senior citizen. (laughter)

ASSEMBLYWOMAN MURPHY: I'm Carol Murphy. I'm an Assemblywoman from the 26th District, and I am delighted to be the Chairperson of this Council and very proud of the people with whom I am working.

We would ask you please-- The hospital asks that any pagers that anyone is wearing please be set to vibrate only. So if you're wearing a pager, please set it to vibrate.

And we will proceed now. Carol Kientz. No, I've said that wrong. Kientz. (indicates pronunciation) Are you here?

Would you like us to hear someone first and give you a chance to get your coat off? (affirmative response from audience) You relax.

Sam Crawford.

I think you will need to use the microphone on that podium, and that puts you into the part of the recording system.

Are you Sam?

**S A M C R A W F O R D:** Yes, ma'am.

ASSEMBLYWOMAN MURPHY: I think that's wonderful. Hooray. Is it Samantha, Sam?

MS. CRAWFORD: Sometimes.

ASSEMBLYWOMAN MURPHY: Okay. Thank you. That's wonderful.

MS. CRAWFORD: Thank you.

Madam Chairperson and distinguished members of the Council: my name is Sam Crawford. I am the Corporate Director of Senior Health Services for the Saint Barnabas Health Care System, the largest integrated delivery system in the state consisting of 10 hospitals, 10 long-term care facilities, and four home-care agencies. We also have the most comprehensive community-based continuum of senior health services in the state. This includes seven adult day health centers, three geriatric assessment/primary care centers, a nonmedical geriatric-care coordination service, and over 100,000 members in our senior membership programs, the Senior Health Network.

Today, in the interest of the caregivers with whom we partner, I would like to address the issue of needed education from three perspectives: multidisciplinary health-care professionals, for community service professionals, and most importantly for caregivers themselves.

Firstly, multidisciplinary health-care and human service professionals. It is a fact that expertise in serving older adults has increased statewide; however, it is not enough. Physicians, nurses, social workers, physical therapists, dietitians, pharmacists, dentists, to name but a few, do not have enough access to educational opportunities which could provide them with information and skill development to work with the elderly and their caregivers. More emphasis must be placed not only on the identified patient, but the identified family; not simply "How is your mother?" but "How are

you?"; with an appreciation for the burden and needs of that caregiver, that caregiver who provides 80 percent of all care delivery in this country and serves as an invaluable resource not only from a financial perspective, but a humanitarian one as well.

Secondly, community service professionals. Education regarding the elderly and their caregivers cannot be perceived as an exclusive need of health-care and human service people. Community service professionals are frequently the very first to become aware that there is a problem with an elderly individual. The police departments of our communities are seeing an alarming increase in the number of confused persons who are found wandering in the streets either on foot or in their cars resulting in avoidable accidents, injuries, and tragically, even death. Most often these public servants do not have access to training or information to enable them to assist these individuals and refer them appropriately. County and municipal workers may be aware that an elderly person is behaving erratically through nonpayment of taxes or public utilities. They may be presented with signs of neglect or abuse but do not have the information they need to recommend an appropriate intervention, and the situation may deteriorate needlessly. And an opportunity for training and education clearly exists.

And lastly and most importantly, caregiver education and support. The effort to address the needs of the caregivers of our state is an ongoing issue. Several years ago, a Caregiver Education Series was promoted through the Department of Health. Various health-care systems and community agencies were called upon to sponsor a series of presentations provided free to current or anticipated caregivers. These presentations were staffed by

multidisciplinary health-care professionals. They addressed critical issues including advance directives, guardianship, normal aging, available resources, alternative living arrangements, and support groups. The cost to the State was minimal and offered enough incentive to the providers to assist in offsetting the cost of the series. This program served almost 10,000 persons during the six years it was available and should be reinstituted as a State initiative.

Additionally, there is a real need for practical training of caregivers who provide physical care to a loved one in the home. Most of our hands-on caregivers have no training or support on how to adapt the home environment to a chronically ill, high-risk family member. Making the home Alzheimer's proof, using existing resources to facilitate care, medication awareness, hygiene, setting schedules, using good body mechanics to lift and transfer a loved one -- where are these caregivers to learn such skills? For the most part, they have no where to turn. Instructions given to a caregiver in the hospital prior to discharge are frequently information that is not quickly or thoroughly absorbed. Anxiety is high, staff may be rushed, and the principles of learning are difficult to achieve.

I'm suggesting two types of caregiver education, both informational and practical hands-on experience. My recommendation must be a provision also for respite care, which will enable caregivers to attend such events addressing education and support. We have offered excellent caregiver presentations within the Senior Health Network at Saint Barnabas. However, if the caregiver can't leave their loved one to attend when that happens, we are all defeated. In certain instances, we have been able to provide free adult day care through our centers for caregivers to utilize when they attend educational

sessions. If, however, the family member is bedridden, we cannot always intervene. Therefore, my recommendation on caregiver education must include a vehicle or provision for respite care.

Thank you for the opportunity to testify today.

ASSEMBLYWOMAN MURPHY: Thank you very much, Sam, and do you have copies of that testimony that we may have, or a copy?

MS. CRAWFORD: Yes, ma'am. I have 18.

ASSEMBLYWOMAN MURPHY: Wonderful.

MS. CRAWFORD: And I gave them to Peggy.

ASSEMBLYWOMAN MURPHY: Thank you. Thank you so much.

MS. CRAWFORD: Thank you.

ASSEMBLYWOMAN MURPHY: We appreciate it, Sam.

The next speaker will be Carol.

And we have been joined by Senator Bob Singer, who will say hello and introduce himself.

SENATOR SINGER: Hello. Thank you. Welcome to Newark Beth Israel.

ASSEMBLYWOMAN MURPHY: Thank you.

SENATOR SINGER: Just for the record, I work for Saint Barnabas, as one of our fine institutions, and we welcome you here.

ASSEMBLYWOMAN MURPHY: We're delighted to be here, Senator. Thank you very much for that and for the hospitality.

Carol.

**CAROL KIENTZ:** Thank you. Thank you so much for a little leeway in timing, and my thanks to the Chair, Assemblywoman Murphy, and to the members of the Council for this opportunity to speak to you.

My voice is a little lower than usual, fighting the kinds of winter colds that we're probably all running into.

I am Carol Kientz, the Executive Director of the Home Health Assembly of New Jersey, the State's largest and most comprehensive association for home care providers and support services in the community.

Actually, after listening to the previous speaker, you may want to take that caregiver education more seriously than ever. You know in the past, home health nurses, visiting nurses, home care agencies have been largely the source of teaching in the home for those family caregivers and have been doing it quite extensively. The words I bring to you are very difficult ones, and so that caregiver education may take on some added import.

I wish I were bringing a positive message to this Council today, but unfortunately, I cannot. Home care as you and I know it is disintegrating in New Jersey. To some extent, this is happening across the country, but New Jersey seems particularly threatened by the fiscal demands of the Federal and State government. Health-care dollars are limited, and decisions are being made, perhaps unwittingly, to produce a large portion of the needed savings by depleting home care services.

This will impact our seniors and the disabled now and even more so in the next several years, unless there is a conscious decision to assure a reasonable amount of care at home for all of us. Both the elderly and their families have made home care, hospice care, and other supportive services in

the community their first option for long-term and end-of-life care over the last decade. The people of New Jersey, our legislators, and State leaders have been advocates of home- and community-based care, some because they believed it to be the most family-friendly type of care and some because they believed it to be the most cost-effective option. For either reason, we saw both Medicare and Medicaid home care programs in New Jersey grow to meet the need and the demand over the last decade.

That growth was nevertheless conservative. Our home health agencies' Medicare costs per patient remained far below the national average in this state. Our Medicaid program had controls and guidelines to avoid some of the runaway costs experienced in other states. We were able to draw from the State's Casino Revenue Fund for some special Medicaid programs to provide home care support to the seniors in the no care zone, those too chronic for Medicare coverage and with income just above the normal Medicaid cutoff. The Personal Care Assistant Program, the Community Care Program for the Elderly and Disabled, known as CCPED, and the Home Care Expansion Program, known as HCEP, were part of that array of programs.

HCEP no longer exists. A few years ago, the State budget constraints forced the cancellation of all new entrants into that Program. Now the PCA Program is undergoing cutbacks, and the Medicaid Division is reevaluating all patients receiving those services. Several have been removed from the Program entirely in recent months, though their visiting nurses assess them as needing care. Needless to say, home care providers are confused and disturbed by these changes. The patients who are finding services reduced or eliminated may be devastated.



On the Medicare side of home care, the situation may be even worse. The Federal Balanced Budget Act of 1997 included severe cutbacks for health-care services in general and, particularly, in the home health benefit. The cuts were instituted this year and made large reductions in payment to home health agencies based on the reimbursement to those agencies going back to 1993. Since New Jersey agencies had always been conservative providing just the care needed without any excess or fluff, cutting back on basic care raised serious concerns for us in home care. These cuts, which reduced New Jersey home health reimbursement by about one-third for Medicare, meant our agencies had to cut their costs by one-third to survive. They did not want to further reduce the care to patients, nor did they want to cut staff and community service programs. We fought together, our Association, our New Jersey legislators, and many State senior citizen organizations, to get the Congress to rethink these cuts and put back enough dollars to allow our agencies to keep providing the same level of good, safe, conservative care.

Unfortunately, most of our pleas have now fallen on deaf ears, despite our New Jersey Congressional Delegation superb efforts. They were truly wonderful. We did achieve a small increase, but it may be too little to save some of our oldest and best agencies in New Jersey. If you read in the newspaper that your local Visiting Nurse Association is going bankrupt or that the local hospital home care department is being closed, please don't be surprised. The Medicare cutback has sunk many of them into deep debt this year, as they kept providing care and hoping for Congress to change its mind. We do expect home health agency closures in this state in 1999, and we're not

sure any other provider will want to pick up the slack, since they, too, may have to operate at a loss.

What does all this mean for the elderly and for their families in New Jersey? It means that home health agencies will be discharging Medicare patients, and are already doing so, quicker and sicker now, just as hospitals have had to do over the last several years. However, home care was the safety net for many of these hospital discharges. There isn't any safety net after home care, except for admission into a nursing home or family member staying home from work to take care of loved ones.

Medicare officials will tell you this is a scare tactic by home care providers and that the Medicare benefit hasn't been changed. Don't believe them. Cereal boxes are still the same size, but when you open them, there isn't as much cereal inside anymore. On paper, HCFA, the Medicare administration, says nothing has changed. In reality, they are paying one-third less for your home care. You tell me. Is that a change or not?

ASSEMBLYWOMAN MURPHY: Carol, we're coming to five minutes.

MS. KIENTZ: One more paragraph, thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. KIENTZ: Those families with sufficient private dollars will still be able to get well-qualified and well-regulated home care services from our State's providers. That hasn't changed, and their services are expanding to meet the full array of acute and chronic problems people are coping with. But for those in the no care zone, it's back to square one. Home care is shrinking, and unless we as citizens, providers, and government leaders work together to

very consciously decide what we want and how to fund what it is we want, then home care may not be there when you need it. If the people of New Jersey believe that home care should be one of their available options, and if the leaders of New Jersey believe that home care is more cost effective than many other long-term care options, then we must sit up and take notice.

The home care system is being eroded by severe cuts which must be stopped and reversed. This Council may be one of the State's best opportunities to make these decisions, and the home care agencies of this state will work diligently with you to make this system work again for the seniors and the disabled in New Jersey.

Thank you.

ASSEMBLYWOMAN MURPHY: Carol, thank you very much.

MS. KIENTZ: Thank you.

ASSEMBLYWOMAN MURPHY: Do you have copies of your testimony?

MS. KIENTZ: Yes. I believe you have a few, and here's some more here.

ASSEMBLYWOMAN MURPHY: Yes. We have been told they are available.

Thank you very much for coming today, Carol, and thank you very much for testifying.

Susan Feder. If I mispronounce your name, please just say so.

**S U S A N F E D E R:** It's Feder. (indicates pronunciation)

ASSEMBLYWOMAN MURPHY: Feder. Okay. Thank you, Susan.

DR. TOLLIVER: Excuse me, would you tell us who you're representing?

MS. FEDER: Yes. Individual and Family Institute, which is located in Paramus, in Bergen County. It is a practice which serves the needs of, as the title indicates, both families and individuals.

DR. TOLLIVER: Thank you.

MS. FEDER: Thank you, and thank you very much for the opportunity to speak today. In listening to the speakers who went before, it just reminds me once again that we are all individuals within the environment, and it's extremely important I believe to focus on the fact that isolation is something that frequently happens to the aging, especially to the old-old.

The family has been the informal network which has traditionally taken care of its elder members. As we have just heard, this is something that is becoming, unfortunately, challenged and, unfortunately, increasingly difficult for many individuals. There's a change in roles. It's very difficult. We cannot really parent our parents; however, it is important that we be there to be supportive and to enable as much independence as possible during the aging process.

On a personal level, I am a baby boomer, and I'm part of that huge population of elders that's coming down the road. I'm also in the sandwich generation. I currently am the parent to a 12-year-old. My mother is in her 80s, and she is beginning to have chronic health problems, and it's a pressure. What happens when your employer is not understanding and you have to be there for both and you are firmly right in the middle?

I think it's very important to consider alternatives. One vital alternative is foster care for the elder population. It is a situation which allows the individual to continue to be part of not only the community, but also of a family system. Sometimes we do not have the nuclear family to turn to for a wide variety of reasons. Sometimes there are elders who are parenting dependent children, who have their own needs, who are not able to independently sustain their own lives. And sometimes there are people who do not have the biological family. They do not have the chosen family, and yet, they have the need for the human contact. They have a need to be in support and not in isolation.

Through careful screening, foster care of elders is a program that seems to have worked in many states, for instance, such as Oregon. I understand that in the State of New Jersey there is one difficulty if you are taking more than one person into your home; then, your home is then considered to be a boarding home, and then you must apply for a license. I understand that's something that's being looked at more carefully. I think it's so important just to not lose the touch with the human side of this. As a new relationship is formed between the elder-elder and potential caregivers, it's important to increase cognitive stimulation. It's important to provide opportunities to practice all remaining skills of daily life. It's important to be able to practice decision making. It's important to know what is going on with your physical self as changes occur.

These things are more humanly, perhaps is the term, handled within the context of a family. It's important to not have any of the isolation increased and to always, again, consider the individual in the context of the

environment, and in this instance, to be able to provide a second family through a foster situation is something that I think is perhaps one viable alternative for the future.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. FEDER: Thank you.

ASSEMBLYWOMAN MURPHY: We appreciate your being here. I'm assuming you haven't written testimony, but we certainly heard your support. Thank you very much, Susan.

I believe Elio Mancini is the next speaker, and then will be Patricia Mahmarian and Maxine Cohen. I believe they are both caregivers.

Elio.

**E L I O   M A N C I N I:** Through the Senior Health Network of Saint Barnabas Health Care System, there are several community-based programs and services available for older adults. I would like to take this opportunity to tell you a little bit about one of these programs and the tremendous impact it had on my health and well-being.

Several months ago, I was hospitalized for appendicitis and had surgery. I developed a blood clot and a heart problem after surgery, which extended my stay in the hospital. When I left the hospital, my incision was healing nicely, and I had no further complications. However, after discharge, I felt weak and tired most of the time. I live with my wife, and we generally manage quite well. I was having trouble with the everyday tasks. My wife was becoming overwhelmed managing everything on her own. The doctor told me not to drive for the first two weeks. This was a problem because my wife does not drive.

My family was very willing to help, however, they do not live nearby. Our neighbors are older than us and have enough of their own problems. I began to feel nervous about our predicament at home, and we were becoming frightened, isolated, and lonely. I phoned my doctor to tell him of the situation and asked for help. My doctor was concerned that my recuperation would be hindered because of my limitations. Fortunately, my doctor was familiar with the Care Coordination, and he referred me to the Program. Helen, a social worker with my local hospital's Care Coordination Program, contacted me the next day. After an initial conversation on the phone, Helen came to my home and met with me personally. We discussed my situation at length.

Helen was amazing. She listened and understood my situation. She didn't dismiss any of my concerns. Helen was familiar with all the services available to help me through this difficult time. She contacted an agency that provides home care services. We arranged for a home care aide to come to our house three times a week. She helped me getting in and out of the shower and did a little housekeeping for us that gave my wife a break. She also brought groceries. Helen made arrangements with the county bus service for transportation to and from my doctor's office, so I didn't miss a follow-up appointment. Helen also gave me information about meal delivery and services. With all the services in place, we were feeling relieved.

Helen stayed in touch with me to make sure things were going along okay, and she reported back to my doctor. After a month, I finally started feeling up to speed. I was given permission to drive again and to get back into my old routine. Helen continued to call me for two months

afterwards just to make sure I was staying on the road to recovery. I am happy to report that I have completely recuperated, and I credit a lot of that to Helen.

I am very grateful for the Care Coordination Program and the type of services it provides. I know there are many, many seniors who are living in their own homes struggling day in and day out. These people struggle with seemingly basic needs, but these needs, if not met, will cause grave health problems. How am I going to get to the grocery store for food? What if I can't stand long enough to prepare my meals? Where do I turn to get care for an elderly spouse or an ailing spouse? What do I do if I cannot afford to pay for medical care? There are so many seniors who simply don't know where to turn to find the help they need. These people would benefit from this service. The Care Coordination Program's guidance and partnership with physicians keeps seniors healthy, safer, and independent.

The cost of the Saint Barnabas Health Care System's Care Coordination Program is borne by the individual hospitals and grant funding. Care Coordination is a visionary program for the future of our elderly. Seniors are living longer with the strong desire to stay in their own homes. The need to control health-care costs grips us all. Care Coordination Programs are part of the solution to addressing the needs of the elderly in the 21st century. A small investment in Care Coordination saves precious health dollars.

I would personally like to make a request to the members of the New Jersey Advisory Council on Elder Care: Please consider the benefits of Care Coordination Programs and support their efforts by recommending that funding for this type of service is made available by the State.



ASSEMBLYWOMAN MURPHY: Thank you very much, Mr. Mancini. We're delighted that you feel as well as you do and certainly sound strong.

MR. MANCINI: It wasn't that way a couple of months ago, Madam Chairman.

ASSEMBLYWOMAN MURPHY: Well, we're glad that it is now.

MR. MANCINI: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you.

Loretta Melito, who is the Essex County Respite Program Coordinator.

**L O R E T T A   M E L I T O:** Hello. I'm Loretta Melito. I'm the Essex County Respite Coordinator.

I'd just like to say and ask-- We now service the Respite Program-- The Statewide Respite Care Program services, in Essex County, about 150 people, but we do have a current waiting list. There's about 60 to 65 people on that waiting list at this time. We have received money from the State, additional funding, not too long ago, and I thank you and I appreciate it. We have put about 20 people on. So we did have a waiting list of about 80 people, so we are down now to 60.

I talk to the caregivers all the time. That's how I communicate, on the phone, with the caregivers. It's a very, very desperate situation. They are very tired. They need help. We just don't know where for them to turn.

I do provide service for them to give them help. The appropriation that we received was good, and I was able to put some people on, like I said. But what I'm asking, too, is also, can we keep getting this additional money?

Because if I do not receive it-- I can put someone on the Program to use the money or whatever, but if I'm not sure of getting it again, I have to take them off, and that's terrible. I will not do that to a caregiver. That is horrible to give them help and then take it away from them. And that's why we just need to keep continuing to get additional funding to help the people.

Also on our Respite Program we have a cap, which is the amount of money that the caregivers can spend in a year's time. And that cap right now is set at \$3000. I would also like to see that raised a little bit. Three thousand dollars sounds like a lot of money to someone. That only provides four hours a week of a home health aide service. It could be an hour a day. It could be two days, two hours. That is not much time. If someone goes to a medical day care, it's only one day a week. Most day cares don't even accept people one day because it's not beneficial to the recipient of the service. From talking to the caregivers, it's just a very-- I don't have anything written down. I'm not-- I'm just here to-- I talk to them all the time. They're just so desperate. They just need so much time, and they know they can't get 24-hour care. They realize that. I tell them that. They know that, but if we could just get a little bit more and maybe keep our waiting list down -- continue to get our money, additional funding so that we can help them.

Even the ones that work. They have to work. They're children of the caregivers, they have to work today, and they do not want to put them in nursing homes. They would like to take care of mom and dad at home or whatever. It's just a very desperate situation, and we would just appreciate anything that you can help us with.

ASSEMBLYWOMAN MURPHY: Thank you.

MS. MELITO: Thank you.

ASSEMBLYWOMAN MURPHY: You're right. It is a hard situation for them. Thank you very much for being here.

We are joined by another member of the Council at the moment, Roberto Muniz, who is from the Francis E. Parker Memorial Home, in Piscataway, New Jersey.

MR. MUNIZ: Hello.

ASSEMBLYWOMAN MURPHY: Thank you very much for coming.

MR. MUNIZ: I'm sorry I'm late.

ASSEMBLYWOMAN MURPHY: That's quite all right.

I'm going to move two people ahead. We have with us Bev Aubrey and Stewart Aubrey, who is an Alzheimer's patient. Bev is his wife, and they will be coming together to speak to us -- the Aubreys.

**BEV AUBREY:** Hi. In case you couldn't tell, I'm Bev. (laughter)

**STEWART AUBREY:** I'm Stu.

MS. AUBREY: We don't have a formal presentation, but I want to thank you all for letting us speak now because, well, I had a meeting at 1:30 at work, and I was getting a little anxious here. This is a lot more formal than I anticipated.

I am a caregiver, so to speak, but our situation is a little unique in that I'm attempting to hold down a job. I'm a clinical social worker at The University of Medicine and Dentistry here in Newark. So my husband, whom you will meet, Stu, stays at home and is very active and independent at this point, even though he was diagnosed with Alzheimer's over four years ago.

As I thought about some of the things that might help us and I would want to speak about here, I would say that, first of all, transportation can sometimes be a problem for people who have early onset Alzheimer's and who need to be at home and are not able to work. Because, for example, if I'm at work, it's very hard for me to get Stu where he wants to be, things like haircuts, going to doctors, and with early onset Alzheimer's, it's important to maintain that independence. So transportation has been a bit of an issue. And the other thing--

MR. AUBREY: I'd like to add just one more thing to that. And that is that in Union County there aren't any taxicabs in most places and also the same situation when we don't have any people going to -- off the trains. We just don't have even people to get people around. It's a major problem, at least, in Union County.

MS. AUBREY: Along those lines, we have been fortunate in that Stu is able to walk and ride his bike and stay active and play tennis still so that he can manage in most cases, but we know in the future, we're going to need other services that are sponsored by the Alzheimer's Association. And one of the programs that they have started has to do with bringing a person into the home for recreational activities and art. Also, they have a senior companion program. We think this is extremely important for people who want to maintain their independence at home and who can benefit from this who are short of being in a nursing home. So I would recommend that these types of programs be supported and funded in anyway possible, and that you all do work with the Alzheimer's Association to continue the programs that are so helpful to caregivers.

My husband may have other things to say, but we would feel comfortable if you all had any questions, if you wanted to ask him about the disease, what he needs, etc. We would prefer a more informal format, so if you have any questions?

ASSEMBLYWOMAN MURPHY: Are there questions from members? (no response)

MR. AUBREY: Well, I just-- A lot of you have seen us on our little dog and pony show from around the country, and I have done a lot of speaking that is on one man's journey of Alzheimer's. I would like to say just the same for Bev, that anything we can do -- maybe since I'm a sports -- I still play sports -- recreational programs. Transportation is a major thing with me and home companions. Again, I think that the Alzheimer's Association has done great work for me and for many other people because -- in terms of medications and everything else. So that's--

Did you want to say anything else?

MS. AUBREY: No. We have nothing else, unless you have any questions. Okay, thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much for taking time today to come to us. We truly appreciate it. Thank you for all your work on behalf of Alzheimer's victims, too.

Patricia Mahmarian.

**P A T R I C I A   M A H M A R I A N:** Hi. My name is Patricia Mahmarian. I'm a social worker and the Program Director for Alternate Family Care with Visiting Homemaker Services in Bergen County, New Jersey. I'm here today to introduce one of our care providers and her client, who will

talk with you about the Program and her current work at obtaining a boarding home license. She currently has two people in her home, and she has gone through a lot of worry in order to obtain the license.

Briefly, Alternate Family Care has been very successful in providing homes in the community to the elderly who would otherwise be placed in a nursing home. The intimate, family-like environment and individualized attention has been noted by clients and family members who are in the Program.

Clients who are deemed appropriate for the Program are placed in the home of a trained and approved care provider, who assists them with their everyday living needs. The client is encouraged to remain as independent as possible and is encouraged to participate in all family activities.

Alternate Family Care is also a cost-effective alternative when compared to nursing home and assisted-living costs. The private rate begins at \$1800 a month, and there is also the Medicaid Waiver Program, which allows people to be placed in the Program who cannot afford the private rate.

Participants and their family report a feeling of a higher quality of life all around being able to remain living in the community. There is the chance to remain as independent as possible while feeling safe knowing that there is a trained care provider always available to assist with needs.

Unfortunately, though, we found that a lot of people do not see Alternate Family Care as a viable option for long-term care needs. People do not know much about the Program, and there are a lot of misconceptions about it as well. We need to educate professionals in the field. They need to understand and present this option when working with people who are

planning for their future and who are looking for alternative living options for either themselves or their family members.

Alternate Family Care can place up to three people in a home and retain its family-like environment. However, care providers who are interested and capable of having two or more clients in their home have encountered numerous difficulties in dealing with their individual towns. They must first obtain clearance from their towns to apply to the State for a boarding home license. Many towns are reluctant to give such clearance, and it is because they do not understand the Program and its purposes and goals. I have spoken with numerous town officials to try to explain the Program, and many are suspicious of the care provider's intent. Many towns feel that a care provider will open up a group home or a boarding home.

One care provider who has gone through much to obtain her boarding home license is here today to discuss her difficulties and her eventual triumph in obtaining her license, and her name is Maxine Cohen.

ASSEMBLYWOMAN MURPHY: Maxine?

**MAXINE COHEN:** Yes.

ASSEMBLYWOMAN MURPHY: And you have with you Florence Daniels?

MS. COHEN: Florence Daniels.

Gee, I'm wee bit nervous. (laughter) I think it's very important that I be here today.

Hello, everyone. My name is Maxine. I'm quite nervous at the moment. This is my first experience, but it was such an ordeal that I had to come and let somebody know what I experienced. Oh, boy. (laughter) Now,

I have so much paperwork just to keep Mrs. Daniels and Mrs. Bettie (phonetic spelling). She is blind -- can't see, can't drive, can't do anything. I went to the city of Paterson to ask them for a seal to help keep Mrs. Bettie in my place because you really are not allowed to have but one person.

I started in July, and I ended up at the end of November completing the whole experience. But now let me go back-- It would take me 10 years to get through this because, I'm telling you, it was a mess.

ASSEMBLYWOMAN MURPHY: Maxine, I have to tell you, there's only five minutes, so we're going to have to rush through that 10 years together.

MS. COHEN: Oh, boy. Okay. Five minutes?

ASSEMBLYWOMAN MURPHY: Five minutes for each of you.

MS. COHEN: Okay. Well, anyway, I went to the city. They did not know what I needed to get the seal, so that was down. Then, I went to the mayor's office. I went to my attorney. I went to other people. Then, I called the agency up and told them I can't -- everything was just at a dead end because they did not want me to have what I was trying to get. Then, I called my city councilman. Thank God I'm a voter. So she got the ball rolling because, see, I'm a little person, and by me being so little, no one wanted to listen to me. All I wanted to do is be able to work in my home. I'm already under the care of an agency, but to no end-- Okay, I'm getting to it now.

But anyway, I got to the city councilman. She had a-- She helped me because I voted for her. (laughter) But anyway, she helped me to get the ball rolling -- called the people in the city of Paterson to let them know what I was trying to do. But the only way-- I was nervous. I couldn't explain to the



city councilman what I really wanted, so I had her call my agency, which is Visiting Homemakers of Bergen County, because they were so good to me, and let the agency explain what I really was trying to do. She called the city, and that's how I happened to obtain the license. After that, then I had all these people come in, one after the other, and I passed everything. Then, the State came in, and they were very helpful to me.

And I don't want anyone to experience-- The purpose of me being here today is I don't want anyone to ever experience what I had to go through with. It was very hard and very different. It's hard for me to even speak to you because all of you are well educated, and poor little old me -- but, honey, I'm trying to talk for the next person that has to follow behind me. But it should be made easier for people to be able to keep people in their homes, just as long as someone is in charge. But, now, that's my home. Why should I have to go through getting a boarding home license if someone already in charge of me? You're blocking the door of people that want to do this work and cannot do it because they're not going to go through what I went through with. I hope they don't.

What I'm saying to the panel, to the people, to everybody try to make it easier so that people can do this work that want to do it. There's so many people out here that want to keep more than one person.

Now look at Florence. She's happy. She's content. She's satisfied. The other little lady, she's content. She's satisfied. The man wanted to fine me \$5000 if I did not obtain a boarding home license. So, now, I have to struggle very hard for this, just to try to keep her in her home because she

loves being in her home. And I refuse to give her up. That's why I fought so hard to keep her. I almost had a heart attack, but I fought anyway.

But I'm here for the other people that have to follow behind me. All I'm saying is just try to make it easier for the others to follow behind me.

I thank you for your time. I'm ready to go now. (laughter) I'm ready to talk now. (applause)

ASSEMBLYMAN THOMPSON: You make your case very eloquently.

MS. COHEN: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much, Maxine, and, Florence, thank you for coming, too.

MS. COHEN: Thank you, too.

ASSEMBLYWOMAN MURPHY: Barry Moore, University Hospital.

**B A R R Y L. M O O R E:** Good afternoon, everyone. Although I'm employed as Associate Director of Social Work Services at University Hospital, I testify today as a private citizen who is deeply concerned about public policy on elder care.

My 86-year-old mother suffers from Parkinson's disease, osteoporosis, and several other medical conditions. She is very weak, experiences constant tremors, is at times short of breath, and often suffers from neck and back pain. Her mental condition is excellent, but her body is falling apart. She can only live at home with 24 hours of care per day. She is more fortunate than most, since she is currently able to afford care at home. However, her financial resources are fast dwindling. When they are gone,

there will be no other choice but to place her in a nursing home under institutional Medicaid. With all due respect to nursing homes and the care that they provide, the care there will be less personal and less responsive than it is now with one person dedicating herself to meeting my mother's moment-by-moment needs.

Virtually everyone would agree that the best place for older adults who need assistance with activities of daily living is in their own homes in most instances. Yet, public policy militates against this universally held value. For example, Medicaid will pay for those financially eligible to live in nursing homes, but will not pay for those same people to remain in their own homes with 24 hours of custodial care, even though the latter would substantially be less expensive than the former. Forcing those who need such care into nursing homes makes no financial sense, let alone humane sense. Substantial tax dollars could be saved if Medicaid were to pay up to 24 hours of home care services, and older adults would be able to enjoy a better quality of life in the process.

On a related topic, in order to qualify for virtually every governmental assistance program, one must meet a rigid income and resources cap. Whether the program be the Prescription Assistance for the Aged and Disabled, one of the several Medicaid Waiver Programs, or institutional Medicaid, if one's income and resources exceed the caps, that person is totally ineligible. There are community services that are provided on a sliding scale basis so that people can access them based on their ability to pay. Why cannot governmental programs be provided to older adults on this basis? Thus, those

whose income and resources exceed the caps could receive services on a copay basis. A basic sense of fairness calls for such a change in public policy.

Thank you for allowing me to present my views on how to provide better elder care in New Jersey.

ASSEMBLYWOMAN MURPHY: Thank you. Do you have a copy of that?

MR. MOORE: Yes. I gave it to--

ASSEMBLYWOMAN MURPHY: Thank you very much. We appreciate that very much. Thank you for coming, Barry.

Gretel Weiss, Older Women's League, Watchung, New Jersey.

**G R E T E L D. W E I S S, Ph.D.:** I dislike these podiums because as you grow older at least some of us shrink considerably. (laughter) We can't be seen above (indicating height of podium), so I'll have to stand to the side.

Good afternoon, Assemblywoman Murphy and distinguished members of the committee (*sic*). I'm Gretel Weiss, a retired sociologist, and I represent the Older Women's League, OWL. Founded in 1980, OWL is a national membership organization focused on midlife and older women, with chapters in most states including New Jersey. Through education, research, and advocacy, our members work for changes in public policy to eliminate the inequities women face as they age. In 1986, I convened the Central New Jersey Chapter of OWL, and in our 12-year history, we've been actively involved with Federal and State issues. I was a delegate to the 1995 White House Conferences on Aging, and I am presently a member of the New Jersey EASE Advisory Committee and the Interagency Council on Osteoporosis, both in the Department of Health and Senior Services.

I'm sure you're all aware that many of the elder care issues of concern affect largely women. When I taught gerontology classes years ago, it became clear to me that it is not an exaggeration to say that aging is largely a woman's issue, particularly in the area of elder care. Women are the primary caregivers for aging spouses, parents, and other relatives, often at a time of their lives when they themselves are aging and becoming frail or while working full-time and caring for younger children. With full-time work a necessity, with fewer children, and much geographic mobility, fewer family members are available to care for their elder relatives.

A woman who has reached 75 is quite likely to be a widow; although, most men her age are married. Thus, in general, living alone is the norm for women over 75. According to the Women's Research and Education Institute 1998 report *Older Women: The Economics of Aging*, women over 65 are more likely to have a severe disability than their male counterparts and to need help with activities of daily living. It is also well known that the financial resources of women are much lower than the resources of men at all life stages but particularly as they age. Longevity tends to drain the resources of both men and women, but it is most likely to exhaust the resources of older women living alone because of their longer lives and their concurrent higher levels of disability and their widowhood.

Thus, the over 75 population continues to grow. The need for more services, as well for funding for these services, continues to grow as well. There are many issues that need to be addressed, but I would like to focus on a few briefly.

OWL believes strongly that older women and men still independent or no longer able to fend for themselves should have alternatives available to them to match their needs and their preferences. The State has been working to develop these alternatives for some years, but the questions of how to implement them and how to pay for them remains.

One of the ever present needs is housing. As we have seen, older women tend to live alone with their limited resources diminished further. For many, the preference is to remain in their own homes if they can afford it and if they can get the necessary care when they need it. The State needs to develop a program to pay for this care, perhaps on a sliding scale, which allows older women and men above the poverty line but with limited funds to get home care to allow them to stay in the community without impoverishing themselves. The last speaker commented on that as well. There is also a continually growing need for affordable housing with availability of assistance, as it becomes necessary, to allow for aging in place.

Another choice is assisted living, which tends to be too expensive for most older women and men. Almost all has to be paid privately. There is however, so I understand, Medicaid money for 1500 slots available which is not being utilized. Assisted-living facilities can accept residents on Medicaid but are not obligated to do so. It is believed that competition will induce the facilities to accept clients on Medicaid eventually, but in the meantime, hundreds cannot avail themselves of this attractive option. Approval for a license for an assisted-living facility should include a mandate to accept a certain number of Medicaid clients as other long-term facilities are required to do.

One of the biggest problems older Americans have faced is how to get information to many of their pressing questions. These questions range from the nature and eligibility of available services to an assessment of their physical, economic, and social needs to arrange for the most suitable living and care situation for them. The question has always been where to turn for this help without having to call many different agencies and without being confronted with an impersonal voice.

ASSEMBLYWOMAN MURPHY: Excuse me, Dr. Weiss, we're coming to the five.

DR. WEISS: Okay. May I finish my paragraph?

ASSEMBLYWOMAN MURPHY: Yes, you may.

DR. WEISS: This is extremely difficult to negotiate for a frail, elderly person and even for their overburdened families. Fortunately, we now have New Jersey EASE, Easy Access, Single Entry, which makes it possible to call a single number to speak to a real person and to get the needed answer. However, the status of EASE, still in its infancy, is tenuous. There are no regulations or statutes to make it permanent. There have been funds by the Robert Wood Johnson Foundation for planning and State implementation but no money for the counties where all the action takes place. Additional funds for the counties are needed, particularly for care management. The State needs to pass laws with funding which make New Jersey EASE permanent for each county.

Thank you for this opportunity.

ASSEMBLYWOMAN MURPHY: Thank you very much for being here, Dr. Weiss.

We have also been joined by the Commissioner of the Department of Health and Senior Services, Len Fishman, who is here with us now.

COMMISSIONER FISHMAN: Thank you.

ASSEMBLYWOMAN MURPHY: Would you like to say something?

COMMISSIONER FISHMAN: Well, I-- Let me start by apologizing for being late. I caught the last three folks who have testified, and it's very gratifying to hear from a wide variety of folks and to see that what we're hearing from the general public is indeed the direction that the Department of Health and Senior Services, under the Governor's leadership, is trying to head in, which is to create more options in the community. I hope that for the first speaker that I heard, Maxine, we will have legislation to drop in the Legislature very soon to avoid the problem that you had to go through so that more people can offer care to more people in their homes.

I look forward to hearing from all the other speakers, but I have to excuse myself for just a moment, Madam Chairwoman, and then I'll rejoin you. Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much, Commissioner.

Rella DeSimone, caregiver for your brother-in-law, and then I am going to shift in my rotation to ask Tracy Baroni to come and speak. Tracy has come up on a train from Washington, D.C., and must return. So we're going to put Tracy in after we have heard from Rella.

Thank you, Rella.



**RELLA DeSIMONE:** Hi. My name is Rella DeSimone. I'm from Irvington, New Jersey. I'm here to ask you to support the programs like Saint Barnabas System's Care Coordination. This Program is for frail, older adults and helps them to continue to live in the community. One of them is my brother-in-law, Frank.

Frank is 68 years old and single. He has had many medical problems in recent years. He has had a pattern of repeated falls, which resulted in a fractured hip and a fractured jaw. He has cardiac problems. He is hard of hearing because of perforated eardrums. He has also been legally blind since 1985. Frank used to be able to live alone in a senior citizen's complex. His medical problems have recently gotten worse, and he has not been able to do well emotionally either. Now he can no longer live alone. So his brother and I have taken Frank into our home.

At first, I was encouraged to place Frank into a nursing home. We felt, however, that Frank was better off at home with his family at this stage of his life. We didn't know what to do, though, because Frank needs more help than we can give, especially since we both must work. When we looked for help to take care of Frank, we didn't know where to turn. We were lucky to find the Care Coordination Program of the Saint Barnabas System. Frank's care coordinator provided me with information and helped us link up with services like CCPED, PAAD, charity care, geriatric assessment, adult day care, a senior wellness program, the Commission for the Blind, and transportation to doctors' offices. Eventually, we intend to use respite services for when we need a break. This Program was able to guide us through the absolute maze

of services. Also, our care coordinator worked closely with Frank's doctors, so his social service programs are coordinated with his medical care.

In conclusion, I want to thank the Council for hearing my testimony. I would like to encourage those who are concerned about frail and elderly seniors to support programs like Care Coordination.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much for coming up today, Ms. DeSimone. We appreciate it.

MS. DeSIMONE: Thank you.

ASSEMBLYWOMAN MURPHY: Do you want me to copy that testimony? Oh, we have. Thank you. Thank you. Thank you. I just don't want to lose anything. We need to read things later.

Tracy Baroni is the Director of Policy at PhRMA, and she's here from Washington, D.C.

**TRACY BARONI:** Thank you very much.

ASSEMBLYWOMAN MURPHY: Thank you, Tracy.

MS. BARONI: I'm not older and shrinking. I've always been this tall (laughter), and I have on one-inch heels.

Assemblywoman Murphy and members of the Council: thank you for the opportunity to present information on a number of issues of importance to this Advisory Council and the citizens of New Jersey. I am Tracy Baroni, Director of Policy for state issues for the Pharmaceutical Research and Manufacturers of America. PhRMA represents approximately 100 of the country's leading research-based pharmaceutical and biotechnology companies, which are devoted to creating new medicines that allow patients to

lead longer, healthier, and more productive lives. Investing more than \$20 billion this year in discovering and developing new medicines, PhRMA companies are leading the way in the search for cures.

And of particular interest to members of the Council and those in attendance today is that New Jersey is home to 10 of the largest U.S.-based research pharmaceutical companies.

I would like to speak about three separate, but interrelated, topics today: the effect of pharmaceuticals on the elderly and the health care system and the importance of access to pharmaceuticals; manufacturer patient assistance programs in existence to help patients acquire necessary drugs; and drugs in development for diseases that affect seniors.

In 1920, life expectancy at birth was 54 years. By 1965, life expectancy had increased to 70 years. The average American born today can expect to live more than 76 years, and life expectancy has risen dramatically for all age-groups. Much of this progress can be attributed directly to innovative pharmaceuticals.

Major diseases such as AIDS, Alzheimer's, arthritis, cancer, depression, diabetes, heart disease, osteoporosis, and stroke afflict millions of Americans and cost society more than \$640 billion annually. The aging of baby boomers will dramatically increase the population potentially at risk for a variety of diseases, including cardiovascular disease.

Pharmaceuticals are an essential and cost-effective component of health care. As an integrated part of a comprehensive health plan, the appropriate use of pharmaceuticals can decrease nondrug costs associated with acute and chronic disease. By decreasing the need for hospitalization and

rehabilitation, pharmaceuticals provided by a health-care plan oftentimes pay for themselves.

Estrogen replacement therapy costs approximately \$3000 for 15 years of treatment, while treating a hip fracture costs an estimated \$41,000. Medicines available today, both hormonal and nonhormonal, can help women remain active and independent while saving health-care dollars.

About 70 percent of Americans over 65 now suffer from cardiovascular disease. The continuation of this trend, combined with the over 50 million Americans expected to be over 65 years old in the year 2020, will put approximately 35 million people at risk for cardiovascular disease in 2020. At this time, the direct and indirect cost to Americans of common types of cardiovascular disease is estimated at more than \$274.2 billion annually. The commitment to battle heart disease and stroke with research aimed at developing new medications and identifying new uses of existing medications is now shared by 63 PhRMA member companies.

A study sponsored by the National Institutes of Health found that treating stroke patients promptly with a new clot-busting drug nets an average savings of \$4400 per patient by reducing the need of hospitalization, rehabilitation, and nursing home care. According to NIH, greater use of this medicine could save the health-care system more than \$100 million per year and reduce the damaging effects of stroke on countless victims.

Increased use of drugs may also be able to prevent some strokes entirely. A study by the Agency for Health Care Policy and Research concluded that increased use of a blood-thinning drug would prevent 40,000 strokes a year saving \$600 million. The lifetime cost of a stroke for a single

patient exceeds \$100,000, a figure that does not include the individual pain and suffering endured by a stroke patient during rehabilitation nor the nonmonetary changes in lifestyle necessary following a stroke. The average annual costs of treatment with a blood-thinning drug, including monitoring, is \$1025.

Deaths from heart disease decreased by more than 30 percent from 1980 to 1990. Nearly 50 percent of the decrease was due to advances in medicines. A University of Maryland study found that patients treated with beta-blocker drugs following a heart attack were 40 percent less likely to die in the two-year period following the heart attack than the patients who did not get the drugs. According to another study, use of beta-blockers resulted in an annual cost savings of up to \$3 billion in preventing second heart attacks and up to \$237 million in treating angina.

A Scottish study on the prevention of heart disease found that using cholesterol-lowering drugs for patients with high cholesterol levels who had never experienced a heart attack can reduce the risk of death from heart attack by 31 percent and the risk of death from all cardiovascular disease by 32 percent.

Pharmaceutical discoveries have been nurtured by growing investments in research and development by pharmaceutical companies. *R* and *D* expenditures by research-based companies are projected to reach \$21.1 billion in 1998. In addition to this vast investment in research and development, which is the largest percentage of sales invested in research by any domestic industrial sector, the research-based pharmaceutical industry has had a long-standing tradition of providing prescription medications free of

charge to physicians whose patients might not otherwise have access to necessary medicines. To assist physicians in identifying the growing number of programs available for needy patients, PhRMA member companies created a directory that lists company programs that provide drugs to physicians whose patients could otherwise not afford them.

Individual pharmaceutical manufacturers determine whether a medication is listed in the PhRMA Directory of Patient Assistance Programs. Drugs not listed in the directory may or may not be available to physicians under this Program. Additionally, each company determines the eligibility criteria for each of its programs. This directory can be accessed by anyone via our Web site at [www.phrma.org](http://www.phrma.org).

In 1997, 39 new drugs and 10 new biologics were approved by the Food and Drug Administration. Of these, 4 treat high blood pressure, a condition that afflicts over 50 million Americans, and 8 target heart disease and stroke, leading killers of older Americans.

ASSEMBLYWOMAN MURPHY: Tracy, I'm going to give you cautionary time.

MS. BARONI: Are you warning me?

ASSEMBLYWOMAN MURPHY: Yes, I am.

MS. BARONI: I'd just like to briefly mention some of the drugs that we have in development. There are more than 300 new medicines for cancer in development and more than \$1.4 billion invested on research into new ways to fight cancer in 1997. There are 27 medicines in development to prevent osteoporosis. Parkinson's disease, there are 12 additional new medicines now in development. Alzheimer's, there are 16 new drugs to treat

patients with Alzheimer's. Twenty-one new medicines target diabetes, which claims the lives of some 42,000 older Americans each year, and there are 24 new medicines in testing for arthritis, which affects nearly half of Americans age 65 and older.

Thank you for this opportunity to present testimony today, and I could answer any questions that you may have at this time. Thank you.

ASSEMBLYWOMAN MURPHY: Sam, Assemblyman Thompson.

ASSEMBLYMAN THOMPSON: Madam Chair, yesterday I was speaking with the New Jersey Technology Council. I commended them, and I commend you, on the success that medical science, the pharmaceutical industry has had in developing means to extend the life of individuals. You cited the statistics on how more people are living longer. The real challenge, I think, for medical science and the pharmaceutical industry today is to develop a means to assure that people have the functionality as they have the additional years of life and they can have the quality of life. Thus, I think we are perhaps going at a faster pace in extending life than we are in improving the quality of that life while it's being extended. That's what I see as the true challenge for the pharmaceutical industry and medical science.

MS. BARONI: I totally agree with you. I see this as a challenge for the whole industry because a lot of what is now affecting people as they live to be older are things that they've done when they were 20 or 30 and weren't thinking about being 75 or 80. So while the Parkinson's symptoms may not be as bad as they could be or the cancer has been cured, they have joint and knee problems, they have COPD from smoking, other things. So I think a lot of it is education and working with people before they get to that point to help

sustain their body systems longer. We're trying to work on that as much as we can, also.

ASSEMBLYMAN THOMPSON: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much.

MS. BARONI: Thank you.

ASSEMBLYWOMAN MURPHY: And we appreciate your coming this distance for us.

The next speaker is Dominic Gangi.

**DOMINIC GANGI:** I am compelled to state at the very outset that Governor Whitman and this Council are to be complimented for their endeavor to be proactive in trying to prepare for a possible epidemic of Alzheimer's disease in the next millennium, even though the administration is cutting monies to social programs such as Medicare.

Hello, my name is Dominic Gangi, and I live now alone. I reside in Mendham Township, and I am here to tell you that I am a caregiver and have been one since Ida, my wife, was diagnosed in late 1989 with dementia of the Alzheimer's type. At the time of diagnosis, Ida was classified as being in the late stages of mental deterioration, a stage, I am discovering, apparently of long duration and emotionally and psychologically painful for this caregiver to witness on a daily basis. I was the sole caregiver for approximately seven years at home. She is currently a resident of a nursing home. The year before Ida entered a nursing home she attended a day care center three days per week.

One of my greatest concerns, as I reflect back on the experience, was to learn what a caregiver is and how to become an effective one of long duration. If I could have had information from a single source in a



nonfragmented manner to alert me of what my future would be as a caregiver, it would have been of considerable help.

Yes, I read the book titled *The 36-Hour Day*, and some of the scientific literature and lay reports, but they were read after the acute phase, when I needed the help the most, had passed as a caregiver. As my experience as a caregiver increased, I discovered that my medical and overall expenses grew commensurate with the length of Ida's illness. The full awareness of this financial cost of being a caregiver became overwhelming at the time the decision was made that Ida would receive better care in a nursing home than I could provide for her in her own home.

The search for a nursing home was a daunting experience and not only because of cost. I soon learned that there were waiting lists of varying durations before a bed became available. And in the Medicaid-certified homes that I interviewed, there were two waiting lists, one for private-paying patients and one for Medicaid-paying patients. The shorter waiting list was for private paying. However, one could short circuit the Medicaid-paying waiting list by first spending down as a private patient and then become eligible for Medicare or paying up to one year as a private patient before which the institution would consider you as a potential Medicaid patient.

Based upon my experience to date, I would like to submit to the Council's consideration the following concepts as part of their future planning.

1. The establishment of a State competitive granting system to support scientific research to find the cause of Alzheimer's, not its cure. These competitive research grants would be to support nonclinical and clinical

approaches to discovering the cause of Alzheimer's disease. Only nonprofit research facilities within the state should be eligible to compete.

2. The establishment within the State system of an informational center wherein the about-to-be-initiated caregiver and an experienced one can come to satisfy their informational needs. The office of information may contain, for example, the following kinds of data: a listing including costs of all day care centers within the state; a profile and listing, as well as costs, of all certified nursing homes within the state; a listing of all research centers within the state conducting clinical research with experimental drugs; information on what to look for when interviewing nursing homes, and so forth.

3. Financial aid. This aid should not be part of the Medicaid system, for the Medicaid system forces a caregiver to cease being productive and not remain a source of tax revenue for the State. This aid should include payment to non-Medicaid-certified nursing homes that meet current State standards. This should be considered for at least the following reason: from a practical viewpoint, it is probable that there will be an insufficient number of Medicaid-certified nursing homes for future needs; thus, increasing a number of Alzheimer's patients being maintained in homes that may be ultimately unsafe for the patient. Also, the additional stress, both financially and psychologically, placed upon the caregiver, at the very best, will make him or her become a ward of the State.

Thank you for your time and attention.

ASSEMBLYWOMAN MURPHY: Thank you very much.

Shirley Howell.

Following Shirley, Queen Sanders-Phillip will be asked to speak.

**SHIRLEY HOWELL:** Good afternoon.

ASSEMBLYWOMAN MURPHY: Good afternoon.

MS. HOWELL: I do not have a prepared speech for you. I have some notes. I am a caregiver. My husband was a stroke victim five and a half years ago, and he has vascular dementia caused by the stroke. He does not have Alzheimer's, but has had some of the symptoms. I am happy to say that because of some research medication that he was on, through The University of Medicine and Dentistry at Piscataway, for a year and a half, we feel -- meaning myself and the doctors who treated him -- that he has made some improvement. We have seen improvement. Although, in the beginning, I was told that there would never be any improvement. It would only go the one way. That's not so. The propencompaline (phonetic spelling) that he was on as a trial medication did deter the advancement of the dementia which he has suffered. I am now a facilitator of a support group for the Alzheimer's Association at Overlook Hospital, and I also volunteer at the Alzheimer's Office about one day a week.

The day care that my husband attends at Madison, New Jersey, is a very fine facility, and it allows me to do some of the volunteer things that I am doing and to be able to in some way to help others, especially with the support group where people-- I am very free about giving out my home phone number, and I don't mind speaking to people at any hour of the day who need to speak to a support group facilitator or someone who can lead them to information that is valuable to them.

I find that at the help line at the Alzheimer's Association where we answer phones -- I do it one day a week -- that is an education in itself. We are

hearing from caregivers. We also hear from people who think they may have some of the beginning symptoms of Alzheimer's and want to know more about it. We get many calls for information on the At Home With the Arts, which is a program which helps people to stay in their homes and have some sort of recreation, something to do, which is what many of demented people do not have. Even though they may have a caregiver at home, they don't have something to do. And some of the things that the Alzheimer's Association is providing have been very valuable.

I also have heard many stories because of these people who come to the support groups. I've heard many stories about nursing homes. I've heard some bad experiences, and I've heard some good ones. I think that we all need to be aware that the quality of the people who are working in these facilities, these nursing homes and day care facilities, needs to be upgraded, and I think that if the State could help to provide some education and training, the training would be most valuable for people who are working as aides in people's homes and, also, in the nursing homes and in the day care facilities.

I would encourage anyone who could do anything regarding legislation in that area to introduce it and to see that it's passed because it's very much needed. I feel that because most of the employees in these facilities or who provide this aide care are women, and most of the caregivers of today are people with Alzheimer's and other dementias are women that -- this is a women's issue, not only a women's issue, but is very prevalent as far as women's groups are concerned. I feel that we need to take it up and keep going with the ball.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much.

Queen Sanders-Phillip, and following her will be John Cannon.

Good afternoon.

**QUEEN SANDERS - PHILLIP:** Good afternoon. My name is Queen Sanders-Phillip. I work for Senior Services as a Home/Friend Director. I'm a full-time employee, but I'm here on behalf of my mother, who is 85 years old. She goes to day care five days a week. Up until two years ago, my mother was a very vibrant person in the community. Now, she's totally dependent on me and my family.

I have a son who makes sure she gets ready for day care. I'm not living in the home, but I'm there every day. She goes to day care five days a week. She's dropped off at our neighbor, and she stays there, which I pay the neighbor to look after her until I can get there, like 4:00 or 4:30. I take her home. I feed her because my mom is at the stage now she does not know whether she ate or not. She does not know whether she took a bath or not, so I'm there. I make sure she gets her bath, make sure her clothing are clean, make sure she-- Every weekend I take her, on Saturday and Sunday -- I take her to functions with me because my mom at one time was a bingo player, and she still thinks she plays bingo. Sometimes she goes into mood swings that make it-- You don't even know the person at times. But just being an understanding person, I listen to what she has to say. I don't follow her up because if you follow her up you tend to argue.

I also work with seniors, and I know some of the things that they're going through with, and they have children that's far away. They're

always calling about one thing or another, and I listen. But I say to everyone, I'm very grateful of the caregivers support group, which has been an inspiration in my life. But it's a hard thing that when you see your mother and you don't know her at times. My mother is a very frail person. She has gone from a size 12 to a size 6, but I make sure that she eats, but I-- With the church and the people in the community helps me a great deal.

But I say to each and every one of you, you do not know what you're going to be coming to before you leave this world. So it makes a difference in your life when you see what's going on with the people that you knew as a person that was some sort of inspiration to the community and now they're almost helpless. And I know the hardship that's going on, and I say to the Assemblywoman, I thank you for just allowing me to speak and to let you know I appreciate all the areas that have given me information. I'm enrolled in Alzheimer's, and I receive a lot of literature.

Working at Senior Services, I have received a lot of information that has helped me through the two years that I've gone through, the trials, with my momma. I thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much for coming today, Queen.

MS. GREENBERG: Ms. Sanders-Phillip, I particularly want to thank you for the details of your day-to-day caregiving life because I think many of us don't know the minutia of what you do and the stress and the juggling. So thank you for making yourself known.

MS. SANDERS-PHILLIP: Thank you.

ASSEMBLYWOMAN MURPHY: Thank you from all of us.

John Cannon.

**JOHN CANNON:** Madam Chairlady, members of the Council: thank you very much for giving me this time. My name is John Cannon. I reside in Bedminster, New Jersey. My wife is an Alzheimer's patient and has been in nursing homes for approximately four years. She was diagnosed about seven years ago at the age of 62, three years before my retirement. After placing my wife in a nursing home, I sold my home in the Morristown area, where we had resided since 1956, and moved to a town house in Bedminster.

I have run the gamut of caregiving, home care, day care, and nursing home care. I started the only male caregivers support group in the State of New Jersey for spouses and other male caregivers involved with Alzheimer's and other forms of dementia. I also serve on the Board of Directors of the Northern New Jersey Chapter of the Alzheimer's Association, and I Chair the Development Committee.

Aside from the personal trauma associated with caring for a loved one, especially a spouse, the most pressing problem for most people involves the financial demands placed upon the family. To fully appreciate this predicament, one must first understand the nature of this disease and, secondly, the manner in which society has chosen to deal with that knowledge.

There are two misconceptions that are popular in society today. One is that Alzheimer's Disease is a condition that affects old people and is manifested by a loss of memory. The other is that nursing homes are placed where old people reside and spend their time playing bingo, singing songs from the '40s, and throwing bean bags at one another as a form of elderly aerobics.

In rebuttal, I would ask you to consider the following. The Medicare Handbook states, and I quote, “Most nursing homes primarily offer custodial care such as help in eating, bathing, taking medicine, and toileting. Medicare does not cover custodial care if that is the only care you need.” This is an absurd generalization and does not take into consideration the majority of cases where total care is required, not simply helping with normal bodily functions. To help you understand better what Alzheimer’s really is and the role played by the nursing home staff in administering this so-called custodial care, consider a typical day in the life of my wife.

Upon awakening and after her diaper is changed, as one would do with a two-month-old baby, two staff members must dress and move her into a geri-chair without any assistance whatsoever from the subject, as she has no control at all of her arms, legs, torso, or even her head. When placed in the geri-chair, she remains in that position unless moved by one of the attendants. An attempt is made to brush her teeth, which may or may not be accomplished. She may resist opening her mouth seeing that this is not food, or if she does open her mouth, she may try to eat the toothbrush thinking it is, in fact, food. If her head slumps to one side, it will remain in that position until adjusted by an aide. This is hardly what I would describe as custodial care, but it does adequately describe the real functions that go on in nursing homes.

As my time is limited, I will get directly to the point of my concern as it applies to you folks. I believe that subsidization of the private nursing home sector would aid considerably in alleviating the tremendous burden placed upon middle-class families. To the extent that families with some



savings could sustain for a period of time a loved one in a private institution, the burden upon society through the Medicare medium is lessened and the dignity and the independence of the caregiving family is prolonged.

We live in an imperfect world resulting in subsidies provided by government to farmers, to the poor, to the uneducated, and to established industries. Perhaps a reordering of this system should be undertaken to provide subsidies to the middle class during their time of greatest need by way of grants to qualifying long-term care organizations. We educate the entire population without concern about the wealth of families receiving that benefit. Why must middle-class families become impoverished before society acknowledges a similar obligation in the case of dementia-stricken families.

Thank you for this opportunity to briefly express my concerns regarding this important issue.

ASSEMBLYWOMAN MURPHY: Thank you very much, Mr. Cannon. We appreciate it. Thank you. Thank you.

Ellen Coughlin. Ellen. (no response)

Roseann Sans. Roseann. (no response) Okay.

Lorraine Sciara, the Executive Director for the Center for Hospice Care of Glen Ridge. (no response)

It may be a shorter afternoon than we all thought.

Paula Reilly, caregiver, from the Alzheimer's Association. (no response)

Eudie Schachter, from the Alzheimer's Association.

Thank you very much, Eudie. I'm glad you're here.

I begun to think that we were being ignored.

Thank you, Eudie.

**EUDIE SCHACHTER:** I'm glad to be here.

ASSEMBLYWOMAN MURPHY: We are, too.

MS. SCHACHTER: Good afternoon.

ASSEMBLYWOMAN MURPHY: Thank you. Good afternoon.

MS. SCHACHTER: I've listened to a lot of caregivers here. I think maybe I'm here longer doing this job than most people.

My husband was diagnosed in 1979. He was home for about 10 years. I worked. My family joined together in the support of making it possible for him to be as independent as he could be for a very long time. He was involved with day care. It was really interesting in my life that-- I went back to school and became a gerontologist. In 1979, all of a sudden, after a lot of denial, it became pretty obvious that he needed an evaluation. Well, here we are, almost 20 years. In May, it will be 20 years-- In April of next year, he will have been institutionalized. He's been in a nursing home for almost 10 years.

My concern at this point is end-of-life planning. Up until about a year ago, his activity in the day care in the institution in the nursing home was very much like your wife's, Mr. Cannon. He was up and put in a geri-chair and even went to programs. And then in this last year, he's had three bouts with pneumonia, and he is now bedridden. I've made a lot of decisions during these 20 years. The hardest one is saying no more hospital, no more IVs. IVs, why not? Well, you see, Alzheimer's patients do a lot of movement. They pull out the IVs. So the way to deal with that is to tie them.

That's terrible. It's terrible to see. It's terrible for the patient. It's hard for the staff.

When I first studied gerontology, they told me that most Alzheimer's patients lived seven years. We're skewing all the statistics. He's not very alert. He hasn't spoken in maybe five years. I think he knows when somebody comes to his bedside. He has to be fed.

My planning at this point is, is it fair to keep this man alive in his very limited quality of life? I don't have the answers. I think if I had a way to make that choice for him, I would let him go to sleep one night and not wake up. I don't know what more that we can do. I think the State is obligated to give caregivers as much information as possible. I, too, run a caregiver support group for spouses at the Alzheimer's Association in Parsippany. I also volunteer to do programs in a nursing home -- do activity programs. I think it's really important that people know about Alzheimer's patients and about the stress that caregivers live under.

When I put him into a nursing home, I really thought I'm not responsible anymore. It doesn't work like that. You still have the responsibility, and you still care, and it's still stressful.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you, Mrs. Schachter, very much for coming here. Thank you for that. (applause)

Rev. John Ragin, Saint Luke's Church, Clinton Avenue, Newark.  
(no response)

Yvonne Thomas.

Thank you.

**YVONNE THOMAS:** Good afternoon, everyone.

ASSEMBLYWOMAN MURPHY: Good afternoon, Yvonne.

MS. THOMAS: I had some notes written, and Mrs. Schachter reminded me of a million things that I had forgotten. So I'm going to present that to you first.

Number one, my name is Yvonne Thomas. I'm a licensed practical nurse, and I'm a certified massage therapist. I am now taking care of my mother, who is 97 years old and suffers from Alzheimer's. One of the devastating things that has come into my life was the fact that most of the time my mother doesn't know me. I have a wonderful nurse's aide. Time is always of the essence, and when I realized how long this would take, I called because I'm always very limited with time. She was kind enough to let me know that she took care of her afternoon patient this morning so that she could stay with my mother until I got home. That's one of the graces in this life -- people have reached out to help me.

Another thing is that my mother says -- if I have to go out and come in -- "Who is that woman who keeps coming into this house?" She doesn't know me. She also doesn't know where she is. She's always packing to go home. And I think at this point in time, she's packing to go home to her heavenly father.

Another thing that happens is that when there's no caregiver in my house, I can hardly take a bath because I have to keep an eye on my mother or -- I'm sorry (witness crying) -- I take a shower with the door open so that I can keep an eye on what she's doing.

The basics -- I've suffered bouts of constipation, diarrhea, upset stomachs, chest pains, palpitations, blood pressure that has gone-- I'm normally a 90 over 70 blood pressure. There are times when I check it that I'm over 200 because I can't handle the situation anymore. It's gotten beyond me. And I also realized today, when I was driving here, that because of our situation, when my mother passes, I don't even have enough money to bury her because of what's happened to us.

Those are the things that I forgot, so I will now tell you the things that I wrote down that I can barely read.

I reside in Plainfield, Union County. My mom is 97 years old. Over the past five years, I've learned many hard lessons. The greatest lesson is that in spite of my experience in caring for the ill, the elderly, the physically and mentally challenged, when it came time to take care of my mother, I didn't have the wherewithal. I couldn't handle it because it was so different from what I had learned and what I have taught to other people.

Caring for aging parents puts a whole new light on your beliefs, your values, your mental health, your family, and your social life. I have learned firsthand about government bureaucracy. The unfeeling, uncaring, and unknowing agents that are well aware that they have your life in their hands and they really take advantage of you. I also have had the opportunity to meet a very small number of wonderful people who worked tirelessly to help me, to help and service as many people as they can. They have very little time and very little money to do this.

I have learned firsthand about serious depression. I remember as a nurse writing on my patient's chart about patients with suicidal ideation. It's

not worse on somebody else's chart anymore. If at the times that I really became depressed I could have spoken to someone, they would have been writing on my chart about suicidal ideation because I seriously thought of just going to sleep and not having to deal with this situation anymore. But I really believe in God, and that has brought me through. I have a wonderful pastor that has helped me deal with it. I have some former coworkers that help put food on our table because I'm now unemployed. I didn't have the money to buy food many times.

Most of the times I don't have money to pay our bills, and our friends come through. Creditors get on the phone and I think they're especially born to this because I have had them -- several people scream at me that I deserve what's happening to me because I'm not paying my bills. They can't understand that there is no way that I can pay a bill if I have no income. I'm being sued by so many agencies, and I'm being told that my house will be taken away from me. The only fortunate thing about that is my mother never signed the house over to me when my dad passed away.

But because it's in her name, we're also denied so many services. There are things I've applied for, for my mother we can't get because the house is in her name. Services I applied for when I became unemployed, I could not get. I could not get unemployment. I could not get any other help because I have a few IRAs that I can't touch without losing 50 percent of it. I've now started drawing them out because I've devastated my mother's savings, my savings-- I've even had to use the money my mother set aside for my sons to take care of us in our home, to put food on our table, and to pay our bills.

I was fortunate enough to get services from the Alzheimer's Association. We started out with two hours, two days a week, which did not give me time enough to work. We also had At Home With the Arts, which greatly helped my mother because my mother has been a chef. She has taught arts and crafts herself. I cannot get her to do anything, but the people that came in were able to get her to start doing her arts and crafts again. And as long as they are around, my mother functions and she's lively and she sings and she laughs and she loves to tell dirty jokes. (laughter) And if a good looking man comes into the house, she's really after him. (laughter) You don't know she's 97 years old. She loves men. So if you guys really want to get up and at 'em, just come over to my house. (laughter)

I probably forgot a lot of things about caregivers and about things that are happening and about the fear of losing my home, but the one thing I beg you to remember is that a person with Alzheimer's -- they've lost perspective, and most times they don't know what's going on. It's the caregivers that are suffering. The caregivers are the ones that need help. There's not enough help out there for us. There's not enough help--

At the times of my depression, the only thing that really kept me from doing something is the fact that if I tried to commit suicide I wouldn't succeed. I would get an upset stomach. I would end up in the emergency room, and I did not have new underwear. (laughter) That's the only thing that kept me from doing something. And most of the time, I don't have enough gas in my car to drive someplace and go off the edge of a cliff. I'm making it sound funny, but it's a horror. If we don't do something about helping caregivers, we're passing this horror on. Our elders aren't cared for

anymore, and our children are going to be suffering and their children are going to be suffering.

We have to do something. We have to get help. We really desperately need it. Our money is being spent so frivolously. But elders that we're told to respect and that we have life, liberty, and the pursuit of happiness -- is not happening. It's not happening anymore. And if this keeps up, it's not going to happen. Our whole society is going to fall apart. So please whatever-- If you have to write to somebody, beg somebody, stand in front of their door, please do it because we're -- if we don't stand together, we're all going to fall apart.

And I'm sorry, but thank you very, very much. (applause)

ASSEMBLYWOMAN MURPHY: Thank you, Yvonne.

Jack Becker.

**JACK BECKER:** Good afternoon, everyone. My name is Jack Becker. I am also a caregiver of a 91-year-old mom and a support group facilitator for the Alzheimer's Association. I'd like to share with you some of my experiences as a caregiver and as a support group facilitator. It may bring some light to the subjects we're speaking about now.

About seven years ago, my mom was diagnosed with mild cognitive impairment, and finally we were told that she had no judgement, should be placed in a nursing home. She was living in a senior residence. I was given the name of the Overlook Hospital Support Group from the Alzheimer's Association, which I attended with my wife, and I can't say enough about it because the information we got there enabled me to seek out CCPED for my mom, which funded her five days a week at a medical day care and five days



a week with a home health aide. I set it up in such a way that we were able to keep her in the community for three years before she was placed in a nursing home.

The medical day care gave her stimulation. The home health aide was a problem though. We went through eight home health aides before we found one that could meet her needs. This is an issue, of finding, also, in the support group. The home health aides are excellent in their job description, but they have no true understanding of dealing with demented people. There's a communication breakdown, so to speak. The training should be ongoing and continual so that they continually learn the essence of dealing with demented people. When we finally did get the home health aide to work with my mom, the home health aide viewed my mother as the employer. This is a demented person who can't make a choice, doesn't know what's going on. Well, that was soon rectified.

During the interim, I interviewed 11 nursing homes, one of which denied me any tour of the facility because they wanted \$80,000 a year up front for three years. Because my mother was with CCPED and potentially Medicaid, nursing home, they wouldn't show me the facility. I thought that was outrageous. I reported that back to the facilitator of the support group at the time, who in turn was -- her boss was the director of medicine for that nursing home. I don't know whatever happened since.

Let me go on with a few other things we're finding. One, my mom now thinks she's in a hotel where she gets breakfast in bed. (laughter) And that's great. We take her out once a week. I call her every day. She doesn't know that she's gone out at times. She doesn't remember if she's eaten. I told

the story at one of the support groups where we took her out. She had a plate of spaghetti. She held her fork up, looked at the spaghetti, looked at the fork. Finally, after several moments, took a handful of spaghetti, wrapped it around the fork, and that's how she ate. She knew there was an association. Understand these people are losing, very slowly, the ability to understand. They're confused. They're disoriented. It's almost like an ice sculpture of the person slowly melting. It's the same person that's there, but their brain is just melting away.

Mom is very happy now. She doesn't know what she did, but we laugh about it. And just to share some little thing with you, now she's been told that she has some facial hair -- so unlike me of course (referring to beard). I'm taking her to electrolysis. She's 91. I know of the stress involved, but I want her to have that comfort of life, that quality of life. She still has that. She communicates on an emotional level. She doesn't remember who her children are now. She forgets the names of her grandchildren. She's slowly losing it all.

But I want to come back to the nursing home. There's some excellent nursing homes. They're in compliance, but the problem we have is the home health aides or the aides there. I've seen it over and over again where they don't bend down and talk eye-to-eye level with people in chairs. I've intervened in numerous occasions where people who are wandering, lost, combative-- One lady who thought she was on Livingston Street and couldn't find her apartment, I found out her room number and walked her back to her room. The aides, the nurses, the whole medical-providing profession needs to

be updated continuously and educated on dealing with demented people. I think this is of utmost importance.

We find that our caregivers in the support group are running into the same difficulties as were mentioned earlier, the problem that they are caught in the middle. They're not low enough income to get CCPED or high enough income to pay for it outright, but they can't afford more than two days a week of medical day care or social day care. They can't afford the home health aide.

The other points we got were-- One of the issues we find is that people who are dealing with the public, such as security guards in the hospital, are not educated. They are dealing with people that are wandering, and they don't know how to communicate with them. We've had people in the support group mention that they've taken their spouse somewhere and there was a restroom. The spouse went in one door and out another and was lost until they found them. Again, people in the public have learned enough to identify a blind or unsighted individual because it's very easy. A deaf individual is a little bit more difficult, but demented is almost impossible in its early stages because they cover it up and they very easily pass as anyone, you and I, until you really get to know. And I think this is a major issue. So I think the State might consider some form of ongoing education in the area of health care for demented individuals.

I made some notes, but I'm not reading from them. I think that the medical day care did provide structure. It provided stimulation and socialization for my mother. I think that the support group itself gave me the ability to learn so very much over the seven years, and I'm still learning as a

facilitator. I've been facilitating now for three and half years with this constant input from different individuals. Each person is unique, each profile of the Alzheimer's individual unique in itself. There are no two people alike. And the sooner we all learn that-- The caregiver and the Alzheimer's individual make a unique pair and no two are alike.

ASSEMBLYWOMAN MURPHY: Thank you very much, Mr. Becker.

MR. BECKER: Thank you.

ASSEMBLYWOMAN MURPHY: We really appreciate your being here today.

MR. BECKER: Thank you for the opportunity.

ASSEMBLYWOMAN MURPHY: Thank you.

Catherine Macchi.

**CATHERINE MACCHI:** I'm Catherine Macchi from the Office of Senior Affairs in Jersey City. When I first heard of this program, I called Assemblywoman Murphy's office and said that I really was delighted that this Council had been formed, and I really felt that I should say something. But in the Office of Senior Affairs in Jersey City, with the senior population we have, the concern, the problems, as all of you have heard, I just felt overwhelmed. I said, "I really would not know where to begin." The member of Assemblywoman Murphy's staff said, "Well, when you decide where you would like to begin, it will be comforting to know that you will have people who are listening." So I thank you for listening. I thank you for listening to all of the people who have shared so painfully.

My testimony is very simple. I'm going to share stories of two seniors rather than go into all of the problems we have in Jersey City. You don't know the names, but you know the problems. You know the situations because everyone has the same name, it's an elderly person in need. There is one senior who had been ill but had the financial resources to stay at home and have a family who could care for her when the homemaker couldn't. There was another senior who had no financial resources but was fortunate enough to apply instantly for Medicaid and lived happily in her own world in a nursing home with a staff that cared for her because her family couldn't. I am the daughter and the daughter-in-law. I had to get that out of the way because any pain that any of you have and felt caring for a loved one is the same pain that I can almost share with all of the people who call our office.

The interesting thing, though, and the reason that I would really like to share my feelings right now is, as all of this horror was happening -- and it was horror -- with my mother-in-law and my mother and I was-- You have to parent. You do parent the parent. You do change them and do you feed them. And then I would go and I would feed and change my granddaughter, and it was mind boggling. But at the same time I was saying, "But this will never happen to me. This will never happen to me." And when I read the second focus of your Council is that you will now be going to the middle-aged people, and I guess I'm past middle age, but-- What you are going to do is not just the service that you will render for the elderly in need now, but the service that you will give to all of us.

You will force us to plan for our future. You will force us to think about our future. You will force us to go against society, against the norms

that have made this image of being young desirable, of making this image of being healthy something that we all must have or else we're not a part of society. The reality is, aging is a natural, normal process. And any education that you can give to all of us teach us to age gracefully, teach us to age thoughtfully, force us to realize that one day we might be in diapers and how we're going to anticipate that, and what we expect from our family.

In closing, I can only say, as all of us know, it takes more than a village to care for a senior. And in this village called the State of New Jersey, I thank our Governor Whitman and for all of you for caring so much about the problems that do exist and working to solve the problems so that problems might not exist in the future elderly.

Thank you so very much.

ASSEMBLYWOMAN MURPHY: Thank you very much, Catherine, for coming here today.

Sister Susan Landau. (no response)

Maxine (*sic*) Cohen, Essex Valley Visiting Nurse Association.

I'm sorry. (referring to wrong first name) We changed that twice. We're close but no cigar.

**MIRIAM COHEN:** That's because, they tell me, my father ran and had me named before my mother had anything to say about it.

ASSEMBLYWOMAN MURPHY: Oh, my goodness. We must have been around the same time.

MS. COHEN: See, that worked real well. When I-- My name is Miriam Cohen, and I'm Director of Referral Services at Essex Valley Visiting Nurse Association. And when I called the Assemblywoman's office, Ms.

Nelson said to me, as she accommodated my very odd schedule on Wednesdays, that if I would share some personal experiences that I'm having in my own family, we could manage to fiddle with my time a little. So as I was sitting there and listening to folks discuss very serious and very sad problems that require many solutions, I was reminded how lucky I am. So I would like to share some of that good fortune with you.

I am the daughter of an 87-year-old woman, who lives independently in her own apartment and has made, what we call, her own assisted-living facility. She has managed through the good planning that my father did. Two years before he died, he said to me that he knew my mother would outlive him, so it was time to sell their big house and move into an apartment house so that she would be able to manage better when she was alone. And when that did, in fact, come to pass, my mother informed me that she would perish if she moved to New Jersey and certainly Brooklyn was a much safer place to age, as far as she was concerned. (laughter)

However, she is indeed very fortunate. She lives in a building that has a 24-hour doorman. She was able when she became ill to pay for 24-hour home health aide service. There was no insurance support for this, and she would assure me that there would be nothing left of papa's money, but we knew that that was what my father had planned for and what each of the four of us would remind her of that -- because she was still perishing if she would come to New Jersey. So as she began to get healthier, she diminished the home health aide time she required, manages three aides who rotate in and out seven days a week, has someone who comes in and takes her shopping from the building. In addition, she wears one of those devices that she can signal for

help if she needs it. The result is that my mom lives very safely. She uses transportation that is available in a large city -- a serious lack in communities that are suburban in nature.

In that same building lives my 91-year-old aunt four floors below that is suffering from glaucoma and accompanied by macula degeneration, serious osteoporosis and has survived three heart attacks, taught school until she was 80 years old. And now says to all of us, "This is what she saved and planned for." One would hope that our society would not have to have us using all that we saved and planned for to care for ourselves, but she is indeed fortunate that she can. So there is my aunt now able to use the same processes that my mom uses and also that they are able to be friends and companions and probably rivalry very long ago gone away. For, you see, my aunt was divorced, and in those times that was a whisper. And she has no children. So that together they form a unit and are able to care and do for each other.

My third experience is as daughter-in-law. My mother-in-law is 93 years old -- one year ago was moved into -- year and a half -- into an assisted-living facility because she could no longer live alone and certainly didn't wish to move to New Jersey, Washington, or Long Island with any of her three children. She knew for sure you didn't come live with your daughter-in-law. I'm nice, but you don't come live with your daughter-in-law. So then she chose to stay in her apartment by herself, and she became no longer able to live alone. So we discussed with her where she wished to live. And I remember her tears as she moved into an assisted-living facility telling us that she hadn't planned on spending her golden years in a nursing home. We helped her make this decision, which was indeed difficult for her. She's



very, very happy. When she tells me a story for the second time and if you remind her, she said, “So what, you’ll listen again.” (laughter)

Meanwhile, she plays bingo. She has friends. She now wants a hearing aid because it didn’t matter to her before that her hearing was deficient. This assisted-living facility takes real good care of her. She has, however, run out of money, but she’s very lucky. While there is no government support for that, her three children have assumed that responsibility, and we will continue to do so for as many years as she is granted.

So, indeed, I am a very fortunate daughter, daughter-in-law, and niece. I have some good genes. Let’s see if they keep me nice and healthy but, in addition, that we have family that can care for themselves accompanied by family we can help. What would we do if I needed to help my mom who assured me that she didn’t want me to object helping my mother-in-law because she had enough money to last until she was 100, and then we would be concerned. My family has planned on one side, on the other side, and have been blessed by much good fortune. But certainly, we need to have a society that has planned for the needs of its citizens.

I’ll take three minutes. If I don’t go through my statement from the people who pay me, I could be in serious trouble. So let me share this with you because I work in a caregiving organization, and caregiving organizations need to be part of this plan.

I work at Essex Valley VNA, and we serve all the residents of Essex County, Jersey City, Harrison, Kearny, and Bayonne. The majority of our clients live in Newark, Irvington, and East Orange. And we say that we have

a very culturally diverse staff in our agency and we serve a culturally diverse population. Our population relies almost exclusively on Medicare and Medicaid for health insurance. Eighty percent of our clients live in a high crime area and where nurses and our home health aides frequently make visits accompanied by armed security.

We all know that a public health system must provide for the health and safety of its citizens. And your plan, the New Jersey State Plan on Aging, references the need to redirect resources so folks can remain in the community and age in place. A solid, functioning home health-care system is going to be part of that aging in place. And we at a home health agency have very serious concerns about whether or not we are all going to be in position to deliver those very needed services on a national level. Home health agencies are still reeling from the Balanced Budget Act which resulted in an Interim Perspective Payment System, which has drastically reduced the amount of money available and reimbursement rates for us to provide services. We have nationally reported over 1200 home health agencies have closed and are no longer in business. While we can assume that some of them should never have been in business, it's rather presumptuous to assume that over 1200 of them shouldn't have been in business.

The figures that they used to establish reimbursement rates were based on 1993 data. While the Health Care Financing Administration's stated goal in establishing the Interim Perspective Payment System was to reduce fraud and abuse, the result of that policy has not been just reducing fraud and abuse. It has been diminution of the ability of the home health agencies to provide needed care and services. Family caregivers that you have all heard

this afternoon are being asked to provide care at increasingly sophisticated levels while we continue to diminish the amount of skilled nursing care and home health aide care available. If we continue to discharge clients from the hospital to home after shorter and shorter hospital stays, we must allocate dollars that support the provision of home health care that allows an adequate number of skilled nursing visits and adequate amount of home health assistance.

As of January 1 of 1999, New Jersey Medicaid is changing how they reimburse home health agencies for care. We will receive payments only for actual time spent in the home. What is not included in the time is the time required to perform such important activities -- telephoning physicians about their patient's status, confirming orders, travel time, and, oh, my, that necessary required paperwork, the one that requires us to kill at least up to two trees a day. We can't complete this in the patient's home. We will not be reimbursed for this. It has long been known that every visiting nurse takes home hours of paperwork.

While Medicaid states that this is not a reduction in reimbursements, the fiscal impact at Essex Valley VNA is estimated at least 10 percent for Fiscal Year 1999. Then we had discussions with Medicaid officials about our difficulties because we needed to provide security guards for nurses to make home visits. They reached an interesting compromise. In year one, they will give us an add-on for our home visits in those high-risk areas. This is a fascinating way to eliminate crime in the State of New Jersey.

My time is almost up, so I would like to say to you that what we need to do is make a fundamental decision. We need to decide. Do we wish

to have home health services provided for our elderly? Do we wish to restrict care to only those who can afford to pay for it themselves?

Thank you for your time.

ASSEMBLYWOMAN MURPHY: Thank you very much, Miriam. We do appreciate it.

Barbara Havlik, Life Management, Inc., also a guardian.

**B A R B A R A H A V L I K:** Good afternoon. I have to read from my paper because my experience will keep me talking for way over my five-minute limit.

ASSEMBLYWOMAN MURPHY: Okay.

MS. HAVLIK: Too many elderly are isolated, invisible people, imprisoned by old age in their own homes. The elderly have committed no crime, yet, isn't it ironic that those who do commit crimes and go to jail or prison may receive better care than many of our isolated elderly?

Our elderly should not have to live without the basic necessities of life. They should not have to be institutionalized to receive care when all they need is a little help to remain in their home. They should not have to struggle to do the things that active adults take for granted, like reading the mail, paying the bills, shopping, bathing, or taking out the garbage.

I am here as a social worker and as an advocate for vulnerable adults. I am here to be the voice of the frail, isolated elderly, who are not able to voice their concerns, their fears, and their needs to you. I have over 13 years of experience in working with our most vulnerable adults. And I am here because I have had the displeasure of leading, literally, thousands of investigations into abuse, neglect, and exploitation of the elderly. I am also

here because I have been appointed the guardian of an elderly women, who is of no relation to me, because no family member stepped forward and because our Office of the Public Guardian had filled their quota of four new cases of guardianships a month.

I know firsthand the plight of older adults who are isolated, aging in place, and I know of the difficulties and stress felt by caregivers who try to assist their aging loved ones. I know the struggles faced by older adults, how they want desperately to maintain their independence in the community but are lacking the financial, physical, and emotional means to do so.

In order to help our isolated elderly and prevent them from being institutionalized prematurely, I believe we need to find out where they are living and provide appropriate and adequate services to meet their basic needs. We need to educate them about services, resources, and entitlements, and attempt to link them to programs and agencies that can help to enhance their independence. And if we are unable to link them to services because of long waiting lists or stringent eligibility criteria, we should be making a case for those services that are needed but unavailable. How can this be done? I believe we can do this through a concerted outreach effort.

An effective outreach initiative must publicize the need to identify vulnerable, isolated elderly. It should get all ages in the community involved in protecting our older adults. I believe the outreach should also include forums where basic information about programs and services should be offered to caregivers, seniors, as well as younger adults. The outreach must include physically locating the elderly and speaking with them about their needs and their options. We can't wait for the elderly to reach out to service providers.

We need to go to them. The outreach effort needs to be creative, continuous, and constantly refined. Postmen, bankers, pharmacists, Realtors, ministers, utility companies, accountants, lawyer, doctors -- they're all professionals who can help us identify the seniors who need help.

I know firsthand from doing outreach to the elderly that it can save lives and that it can protect the elderly from mistreatment. It can save caregivers from becoming overwhelmed and throwing in the towel. Both the seniors and their family need someone to talk to and someone who will listen. The outreach cannot guarantee services, but it can minimize the isolation of older adults and protect them from a crisis. Outreach can help link isolated, older adults with services that simply provide a daily telephone reassurance call, grocery shopping, or transportation to the doctor. These services may not sound so vital in comparison to home health care or medical treatment, but they are as important -- and even more important because they can dramatically affect the quality of life of our senior citizens.

The State of New Jersey has an excellent Ombudsman Program, which minimizes the mistreatment in long-term care facilities. New Jersey also has a terrific Adult Protective Services Program. And New Jersey EASE is an important first step to providing seniors with a comprehensive service. However, a centralized information and referral service can only be effective if a strong outreach component is developed to inform the public about it.

I have been told that outreach is an effort in futility because we don't have the services to provide to the elderly once we find them, but I don't buy that. I believe that even if outreach only enables us to do a little bit to

help our older adults and to make a case for the services that are actually needed, it is worthwhile.

In addition to the outreach we need to do to our isolated adults in the community, we need to address the needs of the incapacitated older adults, those who are, in fact, no longer able to manage their personal or financial affairs. We need to look after the older adults whose rights have been taken away and whose survival is dependent on the care of a guardian.

There is a crisis in New Jersey with regard to incapacitated older adults. There aren't enough guardians in the State, and we still don't have a way of enticing caregivers to serve as guardians. We aren't able to support the potential or newly appointed guardians, and we aren't monitoring guardians after they are appointed in all counties.

I am advocating that the State create a system whereby potential guardians and newly appointed guardians can obtain information, formal training, and ongoing support. I am advocating for free legal help to represent those low-income caregivers of the indigent, incapacitated elderly, who would like to petition for guardianship but can't afford to do so. A statewide system of monitoring guardianships is needed to protect our most vulnerable adults.

We must spend more time and a little more money on the frail, isolated, and vulnerable elderly. We need to look to create ways to help the isolated and impoverished seniors remain in their homes safely. We need more affordable housing, assisted living, or quasi-assisted living for low-income seniors. We need to shop for the 80-year-old seniors who are afraid they may fall again and break their other hip. We need to find our isolated elderly and

help them live to a ripe old age while maintaining their independence, their pride, and their self-esteem.

ASSEMBLYWOMAN MURPHY: Barbara, I'm going to have to ask you to wrap up.

MS. HAVLIK: There is no question that our seniors are living longer. They are outliving their spouses, care providers, and their friends. They are a proud generation, many of whom refuse to be a burden on their family. They continue to age in place, alone, and without vital services. When they can't get out of bed to cook, they eat cereal. When they can't pay their bills because they can't write out a check or access a bank, they find they are forced to live in the cold and the dark without utilities. When they run out of cereal, they don't eat. When their roof leaks, they become wet and chilled. And when they are too weak to fight off a cold, they get pneumonia and die alone. No one knew things had gotten so bad. No one knew they were there, and they were alone.

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you, Barbara, very much.

Agnes Coleman.

**AGNES COLEMAN:** Hi. My name is Agnes Coleman. I reside in Newark. And about a year and a half ago, I had to go out of state to get my mother who had evidently been suffering from dementia and I didn't know it. It was about two months prior to that. I had to give up my job and I'm unemployed, as one of the ladies here had mentioned. I was with my mother every day, as the kids would say 24-7, and I was very stressed out. My mother



had been admitted to the hospital two times, one, the last time at the hospital, which is here at Beth Israel, someone got in touch with me. And I wish I knew who that person was because they really saved my life.

They got me in touch with the Newark Beth Israel Day Care Center, and they got me in touch with the Council on Aging. The person's name was Loretta. She has already spoken here in reference to the Respite Program. I am now enrolled in the Respite Program, which has literally saved my life. And I hope that it will continue to go on and help all of us as caregivers. The only thing about the Respite Program-- I do have a little complaint that you are allowing -- allotted so many days in day care and so many days of home health care each year. And now, with that, you cannot carry over any of your days that you might have left. Unfortunately, I have one day left for this year. Now, I'm going to lose that day because I really -- what can you do in one day as a caregiver? You can't even go to Atlantic City overnight because you have to pick the person up from the nursing home the next day by 11:00. Now, I would hope or wish that we could carry over at least maybe two days of our respite care into the next year. If you don't use those two days then, you will have to give them up.

Now, another thing, too. I'd like to stress that we need more information. I've heard a couple of people here say today -- more than a couple people say that we need a lot of help when it comes to information. I have to go back. When my mother was coming out of the hospital the second time, this is when I got the information that I was looking for. Prior to that, I had no means of getting any kind of information. I know there was a Council on Aging. I do know that. But when a elderly person is coming out

of a hospital, the caregiver or the potential caregiver will need as much information as they can get to help ease the way for them. The caretaker is under a lot of stress. A lot of times your financial end of your particular business has either been depleted or is about to be depleted.

That's basically what I wanted to say. We need more information. We need information. We need information.

Thank you so much for hearing me today. (applause)

ASSEMBLYWOMAN MURPHY: Thank you very much for coming today, Agnes. We appreciate it.

Ann Kapell. (no response)

Ted Goodman was with Ann.

Joann Rizzo, Morris County Service Providers Group.

Joann, thank you.

**JOANN RIZZO:** Thank you for having me. I am Joann Rizzo, and I am here on behalf of the Morris County Senior Providers Group. The Senior Service Providers Group is a networking collaborative of nonprofit agencies in the Morris County community. We deal with senior citizens and their families on a daily basis and have come to recognize some trends in the unmet needs of this population.

Caregiver education: No matter what your formal educational background is, it seems that no one is really prepared to graduate into caregiving. Getting information on available services, knowing how to apply for benefits, learning how to pace yourself and balance responsibilities -- these are all necessary skills for the caregiver and are almost always learned through

on-the-job training. In addition, the new caregiver is trying to master these skills in the midst of a family crisis.

Family Service of Morris County in partnership with the Visiting Nurse Association has sponsored a seminar series, kind of like a Caregiver 101 class. These two agencies have found that to be truly effective, the series should be ongoing and cyclical so that a new caregiver can enter at any point and not miss out on any of the components. While the cost of sponsoring a seminar of this type is minimal, the results are broad based. The novice caregivers are given the tools they need. They meet others who are going through similar experiences, and the seniors that depend on them benefit from their new-found knowledge.

We suggest the State of New Jersey investigate the possibility of supporting a formal Caregiver 101. A standard curriculum could be developed including the topics of Medicare, Medicaid, N.J. EASE, long-term care, and practical coping skills. The State Department of Health and Senior Services could be charged with identifying and training instructors on the local level and funding their efforts.

Respite care: Even the best caregivers need help and time away from their caregiving responsibilities. Without sufficient respite services, the caregiver is liable to suffer burnout and caregiving may become an unwelcome chore instead of a loving responsibility.

We are using the term respite in the broadest sense, including home health assistance, chore, day care, volunteer visits, short-term stays at facilities, and any of the many services that are available to assist the caregiver by giving them a little time and some peace of mind. For the most part, this

continuum of services is well covered and is available if you have the money to pay. For those seniors who are Medicaid eligible, the array of services is somewhat narrower but usually still sufficient to assist the caregiver in maintaining their family member in the community. It is those in the middle that have the fewest options available.

Our final comment on trends concerns housing. A continuum of housing options must be identified for seniors at all income levels. Too often, seniors living in their family home find that they can no longer afford to maintain it. They often choose to sell the home, expecting that the proceeds will last their lifetime. Very often, these seniors find that appropriate, affordable housing is not available, and in a few short years, the money from the sale of their home is depleted. They face their final years of their life with no money and few options for appropriate housing. Senior apartments, assisted living, and other long-term care facilities should be available to all seniors, regardless of their income level.

The State needs to examine its priorities and choose wisely. If the choice is to maintain seniors in the community, then respite services and housing options, such as I have mentioned, need to be available and affordable. The Morris County Senior Service Providers Group recommends expanding the eligibility of State-funded respite services, as well as continued financial support for services, that use a sliding scale fee to make their programs affordable to middle-income families.

Thank you very much for your time.

ASSEMBLYWOMAN MURPHY: Thank you very much for coming to testify, Joann.

Beth Tilkin, Glenlora Nursing Home.

**BETH TILKIN:** Good afternoon.

ASSEMBLYWOMAN MURPHY: Good afternoon.

MS. TILKIN: My name is Beth Tilkin. Who will pay for long-term care when we need it? As a social worker in a private pay nursing home and as a middle-aged person with a middle-aged spouse, I worry about how we will pay for long-term care in the future. I know how quickly a few years of long-term care can go through a life's savings, yet, like many working people, my family will never qualify for Medicaid. I believe the answer is long-term care insurance.

I've been think about long-term care insurance lately. My husband turned 50 a few weeks ago, and I know that if we buy now, the premiums will begin at their cheapest. But even at this time, the annual premiums are a struggle to fit into an already stretched budget.

I believe what is needed is to prioritize long-term care insurance, as we do health insurance: tax incentives to employers who offer long-term care insurance benefits to their employees and help subsidize the premiums; tax credits for individuals who carry their own policies. As our population ages, we can all expect to need some form of care. Long-term care insurance is just as important to cover senior health care needs as Medicare, and the time to start planning is well in advance.

ASSEMBLYWOMAN MURPHY: Thank you. Thank you very much for coming to speak with us. Do you have copies, Beth?

MS. TILKIN: Yes.

ASSEMBLYWOMAN MURPHY: Thank you. Appreciate it.

Vivian Nichols, Passaic County Respite Care.

**VIVIAN NICHOLS:** Hi. My name is Vivian Nichols. I take care of a 91-year-old mother. Seven years ago she became ill and forgot how to walk, and she has been bed bound every since. It is a very difficult position. I have two daughters and three grandchildren, and I would like to spend more time with them, but my mother takes constant care, 24 hours. The first two years were the most difficult. I could not get away on vacations, and I was not able to be with my daughter when she had her first child. This caused me to be very depressed and unhappy. This was before I found out about the respite care.

The respite care from Home Care Options saved my life. As the years go on, I wish I had more time to spend with my family. I'm getting older, and it's getting more and more difficult. I try to use the respite time wisely and get as much out of it as possible, but I'm unable to get away most of the time. I can have a few vacations away, but most of the time I have to be with my mother.

Our respite coordinator, Lois, is a very big help. She is ready to help me figure out my allotted time and the best way to use it. She keeps me advised up to date on what time is available. In the past, we used the nursing care options for my mother when we went away, but now she gets more and more confused and disoriented when she comes home, so I get the in-care home, and I can go away for a few days at a time. It's a very difficult position to be in. If I lost my respite care, I think I would lose my sanity because that's what I rely on. Every year I count how much time I have and how best can I use it. Can I get away with my husband? Can I go with my grandchildren?

Can I do any of the things that most of my friends are able to do without thinking?

But in summing it up, there is not enough awareness of this respite program. The first two years I did not know it existed. And when I found out about it and my mother qualified, it changed my life drastically by allowing me to have some free time. Finally, as it stands, respite serves a three purpose. It helps the caregiver, myself, to get away without worrying about adequate care to my mother. Secondly, it helps my mother stay at home and have a better quality of life for that without going into a nursing home. And I think it also helps the State, because if I didn't have respite, I'd have to put my mother in a nursing home. After seven years, I could no longer go on without some free time to myself.

Thank you very much for listening to me, and I hope this program continues.

ASSEMBLYWOMAN MURPHY: Thank you very much for being here today, Vivian. We appreciate it.

John Voyce. Am I pronouncing that correctly?

**LOIS CORWIN:** John Voyce. (indicates pronunciation)

ASSEMBLYWOMAN MURPHY: Thank you.

I wasn't, you're right. (referring to pronunciation)

Sam started us, are you John?

MS. CORWIN: My name is John Voyce -- just kidding. My name is really Lois Corwin. However, Mr. John Voyce had to leave early, and he entrusted his statement to me, which I would like to read to you because his

mother and he are clients of mine in the Statewide Respite Program of Passaic County.

(begins statement) My name is John Voyce, and I am a caregiver for my mother, Mary Millerman, who is 88 years old. The purpose of my presence is to say thank you to Lois Corwin -- thank you, John -- Home Care Options, and to all of the people that are involved in the New Jersey Respite Program.

If I may, let me explain my circumstances by introducing to you my mother Mary. Up until August of 1992, my mother at the age of 81 maintained an independent lifestyle saying that she never wanted to be a burden on me. I am an only child. She had her own apartment in St. Petersburg, Florida, drove a car, had a position on the managing committee for her complex, and kept in touch with her friends.

In August of 1992, she suffered a stroke losing function of her left side. Her face, left arm, and left leg were affected. While in the hospital, she also had to go through ileostomy surgery, which is the removal of the lower intestine, sealed the colon, and is now necessary to wear a pouch. To say the least, she was not in very good shape. She was prepared to leave this earth. That she survived these traumas is, in itself, a miracle.

Released from the hospital, she entered a nursing home, and by the end of October, it was apparent she would not survive in this environment. She had to be around her loved ones. In October 1992, via ambulance, wheelchair on airplane, ambulance service from Newark Airport, I brought her home. Her condition at this time was she had lost 40 pounds in three months. She could only manage three steps with the use of a walker and was very weak.



But through sheer determination, she gained strength and set a goal to be able to climb the stairs of my house so that she could leave the bedroom. I had converted my dining room into a bedroom for her.

She eventually took on chores of cleaning, doing the laundry, and cooking. I just could never let her mow the lawn or wash my car. As time passed, we visited relatives, and relatives visited us. But by 1997, my mother could not take the long car rides so the visiting stopped. You see the elderly and infirmed carry a very debilitating malady, which can be very contagious to the people who care for them; that is called depression. She was infected and so was I. What to do? I inquired at my township municipality and was directed to Home Care Options. Through Lois Corwin, I applied for a grant and after a few months was accepted into the Program. We used three of the services available.

The first service that we used was for a Home Care Option aide to come to the house and help my mother with her personal needs, an area that I am totally incapable of assisting with. Through meeting a series of home aides, we met with Norma Rosado. Though my mother and Norma are of two different worlds, they are of kindred spirits. Norma has become a part of the family. To Norma, I say thank you.

The second service that was used was the Sterling Day Care Center. Suddenly my mother was going to meet new people. It renewed her interest in her appearance, a trip to the beauty parlor, some new clothes. Her spirits became lighted. The attention and personal interest that the people at the Center showed her was uplifting. She now had something to look forward

to each week. My mother became more functional and life became more enjoyable. Plus, there was something new to talk about.

The third service that was used was a nursing home for a three-day stay. We used that service to allow me to attend some out-of-town requirements. I was very appreciative of the fact that she was in good care and I could go away with a free mind.

To summarize, through the Respite Program, my mother was able to enjoy a few months of companionship and care, and I am very appreciative of the extending of the helping hand to me. For as you know, each day the elderly age and each day their requirement increase. (ends statement)

Mr. Voyce said to me personally before he left that he would like to make two statements that perhaps you could think about on the Council. The two statements are: the waiting list is interminable. The waiting from the time that you get your approval -- your financial approval -- which is, of course, my job, until the time that I have a slot open on the Respite Care Program seems interminable. If I could have the financial resources to take in more people on the Respite Program, I would dearly love it.

The second thing he mentioned to me, which I thought was a rather ingenious idea, which only caregivers can think of because I'm coming from the administrative standpoint, is he thought that there ought to be a sliding scale. When his mother came in on the Program, she was ambulatory. Now, unfortunately, she is bed bound. She had a turn for the worse just a couple of weeks ago. If there could be more time for the home health aide to go in, as the patient's condition slides downward, that might be something to

think of, too; that we could have, perhaps, an extension of grant funds for those who have a downhill slide.

Thank you very much. I am very appreciative for you listening to me, and I'll give this statement to whoever gets it.

ASSEMBLYWOMAN MURPHY: Right there. (indicates person)  
Thank you very much, and tell John we said thank you, too.

We have two more people who have signed up. Dennis Joy, I believe it is?

**DENNIS JOY:** Yes.

ASSEMBLYWOMAN MURPHY: Okay. And following Dennis, will be Jean Ward.

And we thank you all for sitting so patiently and for sharing so very much with us.

MR. JOY: Madam Chairwoman, Council members: my name is Dennis Joy, and I am a resident of South Florida and have been for the past couple of years. Although I was born and raised in New Jersey and educated in New Jersey and love this state, I should say I was a resident of South Florida until September, when I realized that there was something wrong with my 82-year-old mother, who was the caregiver for my 102-year-old grandmother. As a consequence, I took a leave of absence, unpaid, from my job and came back to New Jersey to find out what was going on.

What I found out was that my grandmother, who was born -- she will now be going through her second millennium -- in 1896, had depleted all of her resources that were left to her by her husband, who had died approximately 30 years ago, which consisted of passbook savings accounts.

There were no such things as IRAs and 401Ks when my grandfather was working. And as a consequence of her having lived this long and having had some health problems, there was no money left basically. And my mother, who was 82, had depleted all of her resources in caring for my grandmother because my mother had had help that she had paid for out of her resources for my grandmother, to help take care of my grandmother who has had a colostomy, who has had a couple of falls, had hip replacement, etc., etc., etc.

What I found out, though, was that my mother was suffering from severe memory loss problems, and she was having a lot of other physical problems. The breath of fresh air was that for two hours a day someone through Lois Corwin's organization was at the house from the Respite Program. This was a very warm, caring, loving person that my grandmother has a very fond attachment to. And what that allowed me to do during the three months that I've been here is take my mother to various physicians who have diagnosed her now with onset Alzheimer's. She had a myriad of other problems including a fibroid cyst. She has problems with low hemoglobin, and a myriad of physical problems which are now limiting, severely, her ability to care for my 102-year-old grandmother, who is sharp as a tack mentally, but physically just can't take care of herself any longer. She needs help with her personal hygiene, with taking a shower, and things like that.

So the only point that I can make is as a consequence of the help given by the Respite health aide, these two older women are able to live together, the family is able to stay together. But now what I'm doing as the son and the grandson is I'm now a 52-year-old person who is facing certainly my aging, and some of the things I've heard today are very frightening to me

personally. I'm now looking for a job in this area, so I can participate in the care of my mother and grandmother because it's absolutely essential.

But if this Program is cut back and the aide-- They have a grant. Lois Corwin was able to obtain a grant. There's a copay provision in the grant based on my grandmother's \$704-a-month Social Security check, but without that, they both would be in a Medicaid nursing home, which I think would be an absolute tragedy. So I'm here to say that whatever this Council could do to facilitate getting more aide and more financial assistance to people like my mom and my grandma would certainly be greatly appreciated by this soon-to-be-again New Jersey voter. (laughter)

Thank you.

ASSEMBLYWOMAN MURPHY: Thank you very much for coming to speak today, Dennis. We really appreciate it. Good luck on your job.

MS. GREENBERG: Are you an only child?

MR. JOY: Yes.

MS. GREENBERG: You are. That's what I thought. Okay.

ASSEMBLYWOMAN MURPHY: Jean Ward. (no response)

That encompasses our list of speakers, and I cannot believe that it is 3:00 right on the button. This is some sort of a miracle. Well, I think our speakers are great.

Thank you all again. Your personal stories have been very moving.  
(applause)

**(HEARING CONCLUDED)**