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RESPITE CARE IN NEW JERSEY

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

LAKEWOOD, NEW JERSEY

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RESPITE CARE IN NEW JERSEY

MONDAY, APRIL 16, 1990

U.S. SENATE,
SPECIAL COMMITTEE ON AGING,
Lakewood, NJ.

The committee met, pursuant to notice, at 11:15 a.m., at Barton Hall, Leisure Village East, Dumbarton Drive, Lakewood, NJ. Hon. Bill Bradley (acting chairman of the committee) presiding.

Present: Senator Bradley.

Ms. FORD. I want to welcome you all here today on behalf of Senator Bradley and his Aging Committee. We are very pleased to have him in Lakewood.

For those of you whom I haven't met personally, I am Assemblywoman Marlene Lynch Ford, and I represent this district in Trenton. In Ocean County, and in the 10th District in particular, Senator Bradley has one of the highest percentages of people who are in their older years—I won't call them senior citizens, but they are older Americans and they are in need of the services that are the subject of this committee hearing.

I can't thank you enough for bringing the Senate Aging Committee to Ocean County and to Lakewood. I want to welcome you on behalf of the citizens here. Thank you for coming down here and listening to what we have to say.

It is good to see you again.

OPENING STATEMENT BY SENATOR BILL BRADLEY

Senator BRADLEY. Well, let me thank Assemblywoman Ford for her courtesy in coming today to introduce me and welcome me to Leisure Village.

The Committee will come to order. This is a hearing of the Senate Special Committee on Aging, and I particularly want to express my appreciation to the trustees of Leisure Village for allowing us to hold the hearing here today. I also want to express my appreciation to all those who have been willing to come forward and testify, and I want to welcome all those who are in attendance for the hearing today.

We are aging in America. In New Jersey we can not only see the seriousness of the problem for older and disabled people and their families, but we can also find some of the most innovative and effective programs in America right here in New Jersey, responding to the problems of the elderly.

Today I have asked the Senate Aging Committee to solicit testimony about the New Jersey Respite Care Pilot Project. It is a small project by standards of the Federal Government, but it has helped a great many people and has been very special to me personally.

When I joined the Senate Aging Committee in 1979, about 1 in every 10 Americans was over the age of 65. Twenty years from now it will be 1 out of every seven Americans. Some of our greatest medical successes have prolonged and improved the quality of life for our aging and disabled citizens. Their successes have also brought us new challenges to find ways to meet the needs of an older, sometimes frailer population which has fewer young people available to care for it.

Too often when people think of the aging population, the image that comes to mind is of nursing homes that are overcrowded and understaffed. Although the ranks of the institutionalized elderly and disabled are growing, nursing homes are only a small piece of the solution to the puzzle of long-term care. Four out of five Americans with physical or mental disabilities are cared for by family members at home. Through the years I have grown increasingly sensitive to the value of this informal network of loving family caregivers. I see it as the backbone of every community's effort to offer humane and dignified care for its frail citizens. If we as a Nation are to have any effective long-term care strategy—and I hope that we do develop such a strategy soon—it will have to be built on and support this valuable family network.

The New Jersey Respite Care Pilot Project shows us the way to build on the family network, which is why I pushed so hard to first pass the legislation establishing the project, and then again, nearly 2 years later, to make sure that it was implemented.

The Pilot Project was originally funded for 4 years in 1986 and was intended to serve as a resource for the citizens of this State and as a blueprint for other cost-effective, humane programs that would back up the efforts of family caregivers. Since the program formally opened its doors in April 1988 I have heard many touching stories of its support for caregivers. One 82-year-old caregiver was permitted, because of this program, a week of care for her 103-year-old mother so that she could attend her granddaughter's wedding in California. A woman with Alzheimer's Disease received interim care while her husband was hospitalized for surgery. These stories have reinforced my feeling that such services can make a tremendous difference for strong, supportive families that occasionally need some help in carrying on what the burdens of caring for dependent family members.

I asked the Aging Committee to sponsor this hearing so that the Senate could learn more about how the program is working for those who depend on its help and for those dedicated professionals charged with providing the services. Federal funding for the Respite Care Pilot Project is scheduled to expire this year. I want to continue funding the program for two reasons. First, the nearly 2,000 families helped each year in New Jersey need its services. Second, it is a pilot program that deserves a full 4 years of operation so that we can thoroughly evaluate its benefits, as well as any drawbacks it might have, and make changes and push for national implementation.

I would like to establish similar programs for elderly and disabled people and their families in the rest of the Nation because I am convinced that respite care, along with home health benefits and adult day care, forms the nucleus of a humane approach to long-term care.

I come today to hear whether these programs are practical, what we have learned about implementing them and how they are working.

I thank everyone who has agreed to be a witness today. We have three panels.

Before we begin with our first panel I want to welcome to the Senate Aging Committee Jane Maloney, who is Confidential Aide to the Ocean County Office on Aging, and she will read a statement for Phil Rubenstein, Executive Director, Ocean County Office on Aging.

So, Ms. Maloney, welcome to the committee. The floor is yours.

STATEMENT OF PHILIP RUBENSTEIN, EXECUTIVE DIRECTOR, OCEAN COUNTY OFFICE ON AGING, AS READ BY D. JANE MALONEY, CONFIDENTIAL AIDE

Ms. **Maloney**. Thank you, Senator Bradley. I apologize for these people who expected to hear Mr. Rubenstein today. He is celebrating the Passover holiday. He is very saddened that he cannot be here with you.

The Respite Care bill that Senator Bradley has introduced recognizes that caregivers require care, too. Sometimes we ask ourselves, who are the caregivers? The caregivers are mothers, fathers, brothers, sisters, sons and daughters, grandchildren, nieces, nephews, those people who do have their own identities, their own dreams, and their own needs.

We know that the chronically ill experience a vast range of loss due to physical and mental limitations. The caregivers experience similar losses, but we don't always recognize those losses. The proposed legislation recognizes not only the caregivers' losses but the around-the-clock struggle of the pressures of caregiving.

Shortly we will hear testimony from service providers and from the caregivers themselves regarding the critical need to continue the pilot program here in New Jersey. I am very confident that Senator Bradley will take these caregiver stories back to Washington and that he will encourage his colleagues to listen to this testimony and to address these needs.

Senator Bradley, thank you very much for returning to Ocean County, and thank you for your continued support, your involvement, your participation for the needs of the chronically ill and their families within Ocean County.

Senator **Bradley**. Thank you very much.

This is an official hearing of the Senate Committee on Aging, and if you would, please, refrain from applauding during the course of the hearing. This is an information-gathering effort. We would prefer that you abide by the basic rules of the Senate during the hearing. It is a public meeting. Everybody is permitted to attend, but at the same time, it is pursuant to certain rules, and one is that applause—unless it is a particularly important moment, and we will say that is the case with Ms. Maloney—we would hope that you would refrain from applause.

Let me thank Jane Maloney for her testimony. Please give my regards to Phil Rubenstein and tell him I hope he will be able to visit with us next time we are in Ocean County. And I thank you for your comments.

Our first panel consists of Bill Anderson, who is husband and caregiver of Charlotte Anderson; Meredith Wagenblast, who is caregiver of her mother, Beatrice Newbon; Margaret Bodrucki, who is mother and caregiver of daughter Cheryl; and Ann Ferrugiaro, who is the daughter and caregiver of her mother, Katherine.

Let me welcome all four of you to the committee today. Each of you has participated in the New Jersey Respite Care Pilot Project. Each of you have your own personal stories as to what the project has meant to you and your family members, and the committee and the record—which we will take back to the Senate—should reflect the actual life stories of caregivers who have participated in this program. That's why I have asked you to testify. If you could give your testimony, then I will ask questions.

So why don't we begin with Mr. Anderson and proceed right down the line to Ms. Wagenblast and Margaret Bodrucki, and then Ann Ferrugiaro.

Welcome, Mr. Anderson, to the committee. Please feel free to tell us your story and the story of Charlotte Anderson.

STATEMENT OF BILL ANDERSON, HUSBAND AND CAREGIVER OF CHARLOTTE ANDERSON

Mr. ANDERSON. Senator Bradley, I am glad to be here.

I certainly didn't expect to be here today. I am a neophyte with the Respite Program.

My wife has recently been afflicted with Amyotrophic Lateral Sclerosis. It is commonly known as Lou Gehrig's Disease. Her response is "Why me? I can't play baseball."

I don't know if you are familiar with the disease, but it atrophies the muscles in the body and as a result she has lost the ability to walk or stand. She is confined to a wheelchair and requires constant help with many things such as dressing, bathing and use of the toilet to name a few.

Since she has become an invalid all the household chores she formerly performed have been passed on to me. In addition to these tasks, the daily care of my wife and her many needs have become the center of my attention. Needless to say, an enormous amount of time and energy is consumed performing this job.

In early April 1990, I was enrolled in the Ocean County Respite Program at Independence Place in Whiting, NJ. Presently, my wife attends this adult day care center for a 5-hour period once a week. In the limited time I have been associated with this program, I have found it very beneficial to do some time consuming things that I previously had to ignore. This is a program that is very much appreciated by people who have been thrust into positions that are very difficult with which to cope.

In fact, if it weren't for the program I couldn't be here today.

I think the program is very, very important to people with my needs. That's about all I can say, because I am so new to the program.

Thank you.

Senator **Bradley**. Mr. Anderson, thank you very much for offering your testimony. I'm glad the program exists so that we could hear your testimony today. I will ask you a few questions in a few minutes.

Meredith Wagenblast.

STATEMENT OF MS. MEREDITH WAGENBLAST, CAREGIVER FOR MOTHER, BEATRICE NEWBON

Ms. **Wagenblast**. It is certainly an honor for me to be here today. I think the reason that Barbara Wolfson from the Ocean County Board of Social Services, who introduced me to the Statewide Respite Program, asked me to come is that I represent a group of individuals who have been given the nickname, "Sandwich Caregivers." These are normally people in their thirties or early forties who have young children to care for and elderly and ill parents to care for at the same time.

In my particular case, I have three children who are here with me today, over in the front row over there, and my mother, who is 79 and a victim of Alzheimer's Disease.

I first became aware of programs like Statewide Respite 3 years ago when I attended a caregivers meeting sponsored by the Ocean County Board of Social Services. At this time I met Barbara Wolfson. My mother had just recently been diagnosed as having Alzheimer's, and I had attended the meeting hoping to get some good tips about how to better care for her or how to help her remember things. What I found was something entirely different, that shocked me at the time. Instead of necessarily just seeking information on how to help the patients, this group of people was desperately meeting together to help ease the burden that each one was feeling, the toll that Alzheimer's takes on the loved ones.

This was something that I found difficult to understand at the time because my mother wasn't in that situation. When I casually mentioned that I would, of course, be having my mother move in with us when the time came, the group unanimously rejected that idea and said that it would never work, that it would be too damaging to my family, to my children, and that it wouldn't be possible.

So I left there at the time thinking that this group wasn't for me and that I really didn't need these programs. But now, 3 years later, things have changed considerably. For the past 2 years my mother has lived with us. And thanks to the support of my husband, who arranged to have an addition put on our first floor for my mother, I have been able to keep her with us. However, she has experienced a steady deterioration to the point that now she often forgets who I am, is hard pressed to think of who she is, and has the total loss of all abilities, including getting a drink of water. This doesn't mean she can't enjoy socializing with people because she can, but as far as functioning on any kind of an independent basis, she is unable to do that.

Naturally, the problem for me comes in that I have the three children, who have a very active life. They play on six different athletic teams. We have many church activities and scouting and so forth, all the typical things that children are involved in.

My mother requires almost constant attention. For me to leave the home, our home, I really can't plan to do it for more than an hour because that would be about the extent of time that she could be safely home alone.

This past fall I was reaching a point where I really wasn't sure if I was going to be able to continue to do this. Although I hated the thought of having my mother go to a nursing home facility, it was becoming too much of a strain on all of us. It was at that time that I remembered Barbara Wolfson and some of the programs that she had mentioned.

I called her, and she has been wonderful to us. She sent us all of the information that we needed to establish my mother's eligibility for statewide care. She met with my mother and with me, and she designed a program that would best suit our needs, which was time for us as a family to be together.

The plan is that for 6 hours every other Saturday we have a visiting homemaker from Visting Homemaker of Ocean County. I am sure my children can testify to this better than I can, that these are the best 12 hours of the month for us. It is a chance for use to do simple things that other families take for granted, like going bowling or going to a movie together, which otherwise we just aren't able to do. It is also great for my mother because she has someone there who spends 6 solid hours with her. She can tell this person whatever she wants. She goes over old pictures, and it's a wonderful time for her. It relieves the guilt that I would feel in leaving her. Certainly I couldn't leave her alone, but it helps me, helps the children, and helps my mother, and we will be eternally grateful to the program for giving us this time.

Senator BRADLEY. Thank you very much, Ms. Wagenblast.

Margaret Bodrucki.

[The prepared statement of Ms. Wagenblast follows:]

OUR EXPERIENCE WITH STATEWIDE RESPITE CARE

IN SUPPORT OF STATEWIDE RESPITE CARE

I have been asked to participate on this panel for statewide respite care because I represent those individuals who have been labeled "sandwich caregivers." To earn this title, one must be sandwiched between young children and an elderly, often dependent parent. In my particular case, I have three children, ages 5, 7, and 9, and my mother, who is 79 and a victim of Alzheimer's Disease. I also have an extremely patient, loving husband who added on a room and bath for my mother and who has aided and supported me in my efforts to provide care for her and keep our family running as normally as possible.

I first learned of statewide respite three years ago when I attended an Alzheimer Caregivers meeting led by Barbara Wolfson of the Ocean County Board of Social Service. My mother had just been diagnosed as having Alzheimer's Disease, and I had gone to the meeting hoping to learn how to better care for her. What I found was quite different - a group of people suffering great emotional pain and physical exhaustion, who met not so much to talk about caring for their loved ones, but rather how to survive themselves from day to day. My mother had not reached that stage of the disease, and I could not identify with those caregivers' needs or share their desperation, born of sorrow, pain, guilt, and anger. When I casually mentioned that I would one day have my mother move in with us, there was a unanimous rejection of the plan. They all felt it would be a mistake and be too damaging to my family. I didn't understand that then, and so I felt no need to look into the programs they discussed that might in the future be valuable to my mother and to me. I believed I could handle it all by myself, with the help of my family.

Over the past three years, much has changed. Two years ago, my mother came to live with us, just as I had planned. She could no longer dress herself, prepare the simplest meal, or remember where she lived. Since then, she has experienced a slow but steady decline, which has left her a very different person than the mother I have loved so much. At times she forgets who we are, or who she is. Even the tasks that are performed by most of us without even consciously thinking about, she has no idea how to do or why. It is not unusual for her to ask me the same question twenty times in one day. This is a cruel disease that destroys a person's very being and alters the way we feel about her. My heart aches for her and for our family.

Overall, my children have been amazingly good and kind through it all. They understand that it is the illness that leads their grammy to act the way she does and to say the things she does. They still love her, and I know that she loves them. However, that doesn't make it any easier when I have to take important time away from my husband and children to care for my mother. We are a family accustomed to doing everything together and supporting one another in our activities, ranging from sports to church. Since my mother can no longer be left alone for more than an hour, either my husband or I must stay home. Simple family outings like going to a movie, going bowling, spending a day at the beach - none of these are possible. To go away for a weekend is a distant dream. After a while the pressure and emotional strain become almost unbearable.

This past fall, I reached the point where I felt that I had lost control of our lives and that I could not continue to care for my mother at the expense of my children. I find it difficult to even think about having my mother in a nursing home, but I was nearing that decision. It was at that point that I remembered Barbara Wolfson, and I called her and asked for help. She was and continues to be wonderful to us. She provided the necessary forms to determine if my mother is eligible for respite care, which she is, she met with my mother and me to decide what program of care would best suit our needs, and she contacted Visiting Homemakers Service of Ocean County to provide a caregiver for us on two Saturdays a month for six hours each. This has been the answer to our prayers. Not only do we have this free time to look forward to when we can leave the house with a free mind, but also, my mother loves having the caregiver and thinks of her as a dear friend whom she can have all to herself. It has brought joy to us all, and it has given me the break I needed, so that I can continue to care for my mother at home. It is a blessing for which we will always be thankful.

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There are so many across our state and our country who are in similar or far worse situations than we are. People who want to care for their loved ones, but who need a little help and a little hope. If we in our country wish to support the family unit, then we must be willing to provide some assistance. If Alzheimer's Disease strikes as many people as predicted in the coming decades, we will have an unbelievable shortage of nursing home care. How much better for everyone if we can keep these loved ones at home, and how much less costly, too. Sometimes just a few hours of relief a week can mean so much. I truly hope that Statewide Respite andother similar programs can be strengthened and expanded to reach others in need and to let them know that they are not forgotten.

Dear Senator Bradley,

While I was typing my own account, my children decided to write their own reasons as to why they like having Marie, our homemaker provided by the statewide respite program. I thought you might like to hear what they have to say, too. They will be attending the panel discussion and are very excited about seeing you, especially Scott, who hopes you can give him some pointers in basketball! Thank you for being concerned and aware of the needs of others.

Sincerely yours,

Meredith Hagenblast

I like Marie coming because she gives us time to spend with my mom. My mom is nicer if she has had a good day with my grandma. She can come to my soccer games + baseball. We aren't late to important things when shes there.

from,
Scott

I like having marie because We get to go out as a family and do things We coudn't do if Grammy was home alone. And also it gives my mom a chance to have a break from having to take care of Grammy.

Katie

I like having Marie because we get to go with the family together,

Megan

STATEMENT OF MARGARET BODRUCKI, MOTHER AND CAREGIVER OF DAUGHTER, CHERYL

Ms. **Bodrucki**. Thank you, Senator Bradley. I hope this will somehow help your cause.

I am the caregiver for a physically disabled 37-year-old girl who has both Lupus and Multiple Sclerosis. Her Multiple Sclerosis is into the advanced stages. She has been confined to a wheelchair or a bed for the last 8 years.

Until Barbara Wolfson told us about Respite Care, my husband and I were the chief caregivers. You need two people with this girl at all times. Until we got into Respite Care, my husband and I had absolutely no social life whatsoever. With Respite Care, he and I now have—not a lot, but we have a home health aide that comes in 4 hours a day once a week, which means that for the first time in many years he and I can do little things, like maybe lunch together, go shopping together, take a walk on the beach, the things that other people take for granted, but when you haven't done normal things for such a long time they become very precious times.

As far as my daughter is concerned, she was basically living the life of a senior citizen because most of the guests we had in our house were people the age of my husband and myself. She never had any outside contact with people her age. The aides coming in, are her age. My daughter, incidentally, has a college degree, and one of the aides we have coming in has the same major in college, so those two really have a lot to talk about.

It has been a great boon to her spirits to have these people coming in, and it has been a blessing to my husband and me because we can share a few things together that we hadn't been able to do for a long time.

Senator **Bradley**. Thank you very much, Ms. Bodrucki.

Now, Ms. Ferrugiaro.

STATEMENT OF ANN FERRUGIARO, DAUGHTER AND CAREGIVER OF HER MOTHER, KATHERINE

Ms. **Ferrugiaro**. Thank you, Senator, for coming to listen to us today.

My case is similar to so many. I had to leave my job to take care of my mother. She is a victim of Alzheimer's Disease.

I moved to Toms River in 1986 to take care of her; she had gotten to the point where she was not able to do things for herself. Coming down here, I didn't know anyone and thought, "What do I do?" I called the Ocean County Office on Aging to see if they could give me any help. I explained to them how I had come down and why I was here. They very kindly referred me to the Visiting Homemaker Service of Ocean County. They were able to provide respite care service for about 3 hours a week. That was a big help, I was able to get out and do food shopping and take care of my own appointments.

Then about a month or two later I saw an article in a local newspaper about a support group sponsored by the Ocean County Board of Social Services guided by Barbara Wolfson. So I called them, and she said, "Please come and attend one of my meetings and we'll tell you all about it," which I did, and it was wonderful. I met the people and joined the group. We were able to share our feelings and how we were coping. We began to feel less lonely and desperate.

Then in the spring of 1988 I was told about the New Jersey Respite Care Pilot Project, which was really great, because then I enrolled my mother into a day care center. She started by attending 2 days a week, and then went into 4 days. Another wonderful part of that program is that I was able to get 2 full weeks of freedom because the pilot project was able to place her into a nursing facility. This was part of the program and it was great. Twenty-four hours a day mean many sleepless nights. My mother would get up and wander around.

It is imperative that this program be continued for the sake of all caregivers.

Thank you very much.

[The prepared statement of Ms. Ferrugiaro follows:]

HOW I DEALT WITH BEING A CAREGIVER

By Anne C. Ferrugiaro

Like so many caregivers, I had no choice but to retire from the business world to look after my elderly mother on a full-time basis.

I moved to Toms River in May of 1986 and in September I called the Ocean County Office on Aging and was referred to the Visiting Homemaker Service of Ocean County. They provided limited respite for caregivers consisting of three hours of sitting in each week which allowed me to get out of the house for doctors' appointments, food shopping, going to the library, etc. Their services are based on income eligibility. In December of 1986, my mother began attending a <u>private</u> medical day care center twice a week since she was not eligible for medicaid.

From an article in a local newspaper, I learned of a support group sponsored by the Ocean County Board of Social Services called "The Alzheimer's Related Dementias Support Group" which meets once a month.

Here, at last, was a means for those of us in the same situation to share our feelings and experiences dealing with the continual loss associated with dementia.

In the Spring of 1988, the New Jersey Respite Care program became available to help families care for ailing, elderly persons at home. The burden of providing care to an elderly dependent person can be devastating when the caregiver is the only one who is on twenty-four-hour duty.

As the disease progresses, the patient becomes more difficult to handle without help; most of the patients who attend day care facilities benefit from the group contact whether they participate in the recreational activities or just sit among the others.

The N.J.R.C. program provides respite from the daily grind of caregiving. Services such as homemaker/home health aids, companions, adult day care, and a two-week stay for the patient in a nursing home, are included. The two-week nursing home stay is a life-saver for the caregiver. Privacy, uninterrupted sleep, and freedom of activity help the caregiver to recharge the batteries.

Senator BRADLEY. Thank you very much, Ms. Ferrugiaro.

All of you have, I think, very moving stories about how the existence of a Respite Care Program has given you each some breathing room. Let me explore with each of you some of the other aspects.

Ms. Wagenblast, let me ask you—you said you have several children. What has it meant to the children to be able to have respite care for your mother?

Ms. WAGENBLAST. Well, it has meant a great deal to them. We were each asked to write a little testimony as to why we supported the Statewide Respite Program. As I was writing mine on the typewriter, all three of my children were writing up their own little notes about why they liked it, and I included that in the report.

I would say that in all three cases the feeling was that this gave us the chance to do things together as a family. That has always been something that we've done. We support each other in all of our activities. It has been difficult these last couple of years when I—or my husband, but usually I have to stay home—it means a lot to them to have us both there. I think that my son wrote that I am also a much nicer mommy when I have a break from taking care of granny, so I think they would all agree to that, too.

Senator BRADLEY. So essentially, if you have no relief whatsoever in your family circumstance, your children end up getting a little short-changed?

Ms. WAGENBLAST. Oh, that's for sure. I haven't cut back on their activities, really, but I don't know how long we can continue at the rate we're going now, or how long we would be able to continue if we didn't have this break time to look forward to. We take great joy in planning every minute of the 6 hours that the visiting homemaker is there.

Senator BRADLEY. Ms. Bodrucki, how long have you been caring for your daughter in terms of this kind of intense care?

Ms. BODRUCKI. Eight years.

Senator BRADLEY. Eight years?

Ms. BODRUCKI. Yes.

Senator BRADLEY. So it has been an 8-year unrelenting burden?

Ms. BODRUCKI. Yes, because with Multiple Sclerosis it usually just keeps getting worse. So as each year progresses, her condition deteriorates.

Senator BRADLEY. So her needs increase with every year?

Ms. BODRUCKI. Absolutely. The worst has been the last 3 years.

Senator BRADLEY. Just in terms of the amount of time that you've had to spend with her?

Ms. BODRUCKI. Yes, the amount of time that we had to spend with her, and the extra work. There are times when she can help herself a little bit, but with Multiple Sclerosis it is a disease that wavers from hour to hour. She cannot be left alone at any time.

Senator BRADLEY. And that is a similar story to Alzheimer's?

Ms. BODRUCKI. Well, this girl has no problems mentally. These are physical.

Senator BRADLEY. But she requires constant care?

Ms. BODRUCKI. Right. She can't answer the telephone because her hands shake too much. Sometimes she cannot feed herself. Sometimes she can, but you never know for sure what it's going to be like.

Senator BRADLEY. And Ms. Ferrugiaro, how about you? How long have you been taking care of your mother?

Ms. FERRUGIARO. Actually, I would say 10 years. She started quite a while ago, but it was very mild at the time. She didn't live with me all the time. She came up to live with me for about 5 years, and then I had to come down here. I had to leave my job. I was a very active person in my job because I was a manager and an officer in a bank. I was used to the activity around me, and all of a sudden to come down to a place that was alien to me, I had to sit in a house with four walls and one person. I had some help from the Pilot Project.

Senator BRADLEY. Mr. Anderson, you are new to the Program, but you clearly felt the pressure building in terms of the need for constant care for someone who has Lou Gehrig's disease, like your wife?

Mr. ANDERSON. Yes. At times I find myself on edge. I have to bite my tongue, discipline myself in such a way that I do not make my wife anxious. It is good to get a little time away from the patient so that you can go off and do things that are normal. I know I have to take my car to inspection, and the only way——

Senator BRADLEY. That might take longer than you expect, too. [Laughter.]

Mr. ANDERSON. That is usually true.

But with the rest from the program, it will give me the opportunity to take the car to inspection, which I would probably have to ignore without it.

Senator BRADLEY. Well, you know, in the New Jersey Respite Care Pilot Project the thing that is done by the county agency that is in charge of it is that they look at your situation and they determine, among the things that are available to you in terms of adult day care, home health aides, in some rare cases emergency relief through a nursing home, and companions—and each of you essentially talked to the Ocean County agency, and in the conversations you jointly agreed what would be best for your circumstances? Is that how it worked?

[Affirmative responses.]

Senator BRADLEY. Well, let me thank all four of you for your testimony and your stories. I think that you bring to light the need that we talk about. You know, when you hear the word "respite," nobody really understands respite. I'm discovering. What we may have to do is redefine it and say that it's a kind of "relief" program from constant caregiving so that your family, in one case, can have an opportunity for a more complete experience, and in the other case just so that you naturally want to give to someone that you love.

Let me thank all four of you very much.

Our next panel consists of the providers of respite care services. We have heard from the recipients of respite services, and now I would like to call to the witness table Mary Fran McFadden, who is the Administrative Supervisor of Social Work, Ocean County Board of Social Services; Mary Jane Kegelman, Program Director, Independence Place of Whiting; and Barbara Vandenberge, who is the Executive Assistant to the Director, Visiting Homemaker Service of Ocean County.

Let me welcome all three of you to the committee. If you could limit your statements to about 5 or 7 minutes, and then we'll do some questions from the perspective of those who are actually providing the care.

So, Mary Fran McFadden, welcome.

STATEMENT OF MARY FRAN McFADDEN, ADMINISTRATIVE SUPERVISOR OF SOCIAL WORK, OCEAN COUNTY BOARD OF SOCIAL SERVICES

Ms. McFADDEN. Thank you, Senator Bradley. It is a pleasure to be here this morning to speak about this program, and it is also a pleasure to hear so many nice things said about it by the people to whom we are providing the care.

Since the program started in Ocean County in 1988 we have been able to provide services to over 300 caregivers and their families in Ocean County. Those services have ranged from short-term nursing and boarding home stays to day care and in-home homemaker services. Recipients have been young and old, male and female, but they all have one characteristic in common: they are all the primary caregivers for an elderly or disabled person, and they all needed relief from that caregiving.

Respite is not a new idea. It is just a new name for something that has gone on for a long time. Traditionally, respite services have been provided by other family members, neighbors, and friends, but in Ocean County a phenomena occurred in the 1960's, the growth of senior retirement communities. It quickly became apparent that as the "young old" in these communities aged, services would have to be developed to take the place of the support that had been left behind in communities such as North Jersey, Connecticut, and New York, areas from which people were moving to move in to these retirement developments.

Public and private agencies began to identify service gaps as the over-60 population grew to almost 30 percent of the county population. With support from county government and a strong sense that people should live in their own homes as long as possible, funds were provided for some of the most basic human needs. Meals-on-Wheels and nutrition sites were provided for food and socialization. Transportation services for medical needs were developed in the county, and homemaker services were funded to allow people to live with dignity and comfort in their own homes.

Although rarely identified as such, these home services were often part of a plan to provide care for the caregivers, to help them cope with the strain and the isolation of providing health care for an elderly or disabled person.

All too often, though, need exceeds resources, and hard decisions have to be made by agencies about who receives service. On a continuum of need, relief for a caregiver could not always be the first priority. However, the Statewide Respite Care Program ensures that caregiver relief can be viewed as the most pressing need and priority for service.

The financial eligibility guidelines of the program allow a large number of people who are not eligible for other services to receive services under this program, thereby recognizing the expense of this kind of service and the importance of supporting the extensive commitment that families make to caregiving, a value important in our social culture. Private purchase of these services could rapidly deplete resources which are needed for other areas of a person's life, such as house repairs or noncovered medical services.

In Ocean County, as you've heard, the application process is handled by a social worker. In addition to the respite intake process she also provides information and referral for other services for which the family might be eligible. These include—I'm going to list a lot of services, and I'm sure I've left out a few—but these include food stamps, home energy assistance, senior housing security and transportation, Alzheimer's Disease and related dementias support groups, Community Care Program for the Elderly and Disabled, Home Care Expansion Program, Meals-On-Wheels, nutrition sites, outreach programs, adult protective services, New Jersey Care, Transportation Assistance Program, mental health services, and legal services. These programs, as well as hospitals and home care providers, also operate as referral sources for the Statewide Respite Care Program, thus assuring that the largest number of people possible receive services for which they are eligible.

Once an application is completed and approved, an individual service plan is established for the caregiver and care recipient. The needs of each are assessed and services established to meet as many of those needs as possible. The services may be short-term, 2 weeks inpatient in a nursing home, or long-term, 1 day per week of adult day care for a year, up to $2,400 per year/per family cap.

Depending on the financial assessment, a copayment may be required, but individual circumstances are taken into account when the copayment is established and when circumstances change.

The primary focus of the program is to provide relief to caregivers so that a major objective to reduce inappropriate institutionalization is accomplished. Although most caregivers do not want to place family members into nursing homes, the exhaustion of caregiving and the increasing needs of the dependent family members sometimes seem to leave no other choice. By providing even limited services under the Respite Care Program, caregivers can often "catch their breath," regroup, and develop a plan of care that will allow them to keep the family member at home.

Respite services can also help the caregiver and recipient to more readily accept nursing home placement when it is in fact necessary and appropriate. Respite services can be utilized during the preplacement period, and the social worker can provide the necessary counseling during this difficult transition.

With the graying of America and the socially appropriate preference to have disabled people at home, an array of community-based services directed to support a family's right and responsibility to care for its members will become a social necessity. The New Jersey Care Respite Pilot Project is an excellent resource to address a dramatic social need in a manner of sensible public policy and social utility.

Thank you.

Senator **Bradley**. Thank you very much, Ms. McFadden.

Mary Jane Kegelman, who, by the way, is one who runs an adult day care center.

STATEMENT OF MARY JANE KEGELMAN, PROGRAM DIRECTOR, INDEPENDENCE PLACE OF WHITING

Ms. KEGELMAN. Thank you very much.

An estimated 7 million to 8 million adult Americans are now providing personal care to their parents, spouse, in-laws, or other elderly relatives, and an estimated 20 to 25 percent of the employees at any typical U.S. company spend 6 to 35 hours a week on responsibilities to the elderly, equivalent to a second full-time job.

The burden placed upon women is particularly great. Three out of every four family caregivers who tend to the needs of the elderly are women, according to a recent study that was sponsored by the American Association of Retired Persons. That same study found that more than half of these women provide this care while holding down full- or part-time jobs, and nearly 40 percent are simultaneously raising children of their own. We had testimony right here today to this. Statistics show that while these women spend an average of 17 years caring for their children, they can expect to devote 18 years in caring for an elderly parent.

Americans caught between caring for both young and old are called the "sandwich generation," and this group is growing larger by the day as life expectancy increases. Over the next 10 years Americans age 65 and older will increase by 11 percent, while those age 85 and older will increase 42 percent. As more people live into their seventies, eighties, and beyond, more of them will become chronically ill, or possibly infirm, and services must be available to meet their needs.

Respite care is one of a number of strategies designed to prolong the continued community residence of the disabled aged. Respite services can be described as a service or group of services that provide caregivers periods of relief and rest away from the patient. The goal of relieving strain on family caregivers is usually linked to the program goal of avoiding or delaying nursing home admissions, thereby reducing the economic costs of care.

One of the services available under the Statewide Respite Care Program in New Jersey is adult day care. Adult day health care is a coordinated program of health and social services, provided in a home-like setting to elderly and frail adults with physical or mental impairments. Adult day health care provides working caregivers with a positive, sensible, and cost-effective community-based approach to caring for older adults with health limitations. Of equal importance, the support and respite offered by adult day health care enables working caregivers to be more healthy, productive employees.

The overall goal of adult day health care is to promote the independence of the older person to the highest degree possible. Day care is a structured program of coordinated social and health-related services in a protective setting during any part of a day, but less than 24 hours. Providing direct care and supervision, this program addresses individual client needs and is oriented toward prevention, maintenance, or rehabilitation of persons who, due to physical, social, or mental impairment, require community-based supportive services to prevent or delay institutionalization.

Individuals who participate in adult day care attend on a planned basis during specified hours. Adult day care assists its participants to remain in the community, enabling families and other caregivers to continue caring for an impaired member at home.

As to the typical services of adult day health care, we provide or arrange transportation to enable the clients to attend our centers—we will come directly to your home, pick up our clients, and bring them to the center; we develop a specific client day care plan and goals appropriate to the client's individual functioning status and limitations; nursing services, including but not limited to evaluation of the client's needs, routine health monitoring, and supervision or administration of medication; assistance, as needed, with activities of daily living, such as walking, eating, toileting, and personal care. We will even provide bladder and bowel training programs. A daily meal is provided, and supplementary snacks.

Your activity program includes reality orientation. These are activities that are designed to promote the client's awareness of time, space, objects, and persons; resocialization and stimulation; activities to encourage and assist clients to interact with staff and other people; and supportive counseling, which is active listening, attention to the person's needs and suggestions, and guidance to help them interact with others.

Social services will be provided to the clients and the families. This will include psychosocial counseling, information, and referral.

Adult day health centers offer a special place for daytime care of adults who need professional supervision but do not need 24-hour institutional care. They offer fun, friendship, and acceptance to frail or disabled persons who might otherwise be isolated with their problems.

We health professionals have been increasingly concerned that the stresses experienced in caring for a disabled family member may erode the capacity of families to continue providing these much-needed services. Family caregivers may be overburdened and severely distressed. Spouses may be at a greater risk of burden and distress because they possibly are elderly themselves and are likely to have diminished physical capacity for demanding caregiving. Alzheimer's disease and the related dementia disorders are thought to be particularly distressing to caregivers by virtue of the behavior disorders and rapid decrease in functional capacity of the family member.

Adult day health centers provide families and others with assistance, support, and relief from the demands of constant caregiving, as well as helping cognitively impaired older adults to maintain their level of functioning and enhance their quality of life.

As the director of an adult health center, Independence Place in Whiting, I have found that the Statewide Respite Care Program has increased the caregivers' quality of life, has reduced the economic burden upon the caregivers, and enabled working caregivers to be more healthy and productive employees and, most importantly, assisted cognitively and physically impaired older adults maintain their maximum level of functioning.

Without the Statewide Respite Program, many of these families would not be able to obtain the much-needed services that are available under this program. Your elderly caregiver possibly would become physically and emotionally drained, and might possibly become ill themselves. Instead of one frail elderly person, we now would have two, both in need of services.

Adult day health care is cost-effective and has proven to prolong community residence. So look at frail elderly and disabled persons that are caregivers, and the Statewide Respite Program. Put them together, and it works.

I just have one other thing, Senator Bradley, that I would really like to say to you. I'm not too sure if too many people are aware that Senator Bradley is the sponsor on the Medicare bill for adult day health care. This is an article that was written in a magazine, New Jersey Success, and according to this, what he is cosponsoring is 100 days under Medicare to pay for adult day care. What we are looking at here is more availability of services, more people who would be able to be provided with their great needs.

I am going to end my summation on day care and quote you, Senator Bradley. You state here, "Day care programs promote seniors' maximum level of independence by emphasizing their strengths and abilities rather than their impairments and limitations." I couldn't have said it better myself. [Laughter.]

[The prepared statement of Ms. Kegelman follows:]

FROM: Mary Jane Kegelman, M.S.W.
Program Director
Independence Place of Whiting
Adult Day Health Care Center

If you have a parent alive today, sooner or later that parent will need help. It may be financial, medical or emotional. Often it is all three at once. This will have an intense effect, not only on you but your entire nuclear family.

An estimated 7 million to 8 million adult Americans now provide personal care to their parents, in-laws or other elderly relatives. And an estimated 20% to 25% of the employees at any typical U.S. company spend six to 35 hours a week on responsibilities to the elderly equivalent to a second full-time job.

The burden placed upon women is particularly great. Three out of every four family caregivers who tend to the needs of the elderly are women, according to a recent survey sponsored by the American Association of Retired Persons. The same study found that more than half of these women provide this care while holding down full or part time jobs. Nearly 40% are simultaneously raising children of their own. Statistics show that while these women spend an average of 17 years caring for their children, they can expect to devote 18 years to caring for an elderly parent.

Americans caught between caring for both young and old are called "the sandwich generation", and this group is growing larger by the day as life expectancy increases. Over the next 10 years, Americans age 65 and older will increase by 11%, while those age 85 and older will increase 42%. As more of our parents live into their seventies, eighties and beyond, more of them will inevitably become chronically ill or infirm.

The following are some facts demonstrating the impact which family caregiving to older adults has had on the workplace. Consider these facts in the context of demographic trends which indicate an aging, shrinking workforce with an increasing number of females:

- According to the 1989 AARP and Travelers Insurance Company employee caregiver survey, 33% of full-time employees and 37% of part-time employees have lost time from work due to caregiving responsibilities.
- A 1989 Fortune Magazine/John Hancock survey found that 24% of employees stated that they are less productive in their jobs due to caregiving responsibilities.
- Public and private surveys indicate that a substantial percentage of working caregivers are women between the ages of 45 and 54. The middle-aging of the baby boomers will cause the age 45-54 group to grow nearly 50% in the 1990s.

RESPITE CARE is one of a number of strategies designed to prolong the continued community residence of the disabled aged. RESPITE

SERVICES can be described as a service or group of services that provide caregivers temporary periods of relief and rest away from the patient. The goal of relieving strain on family caregivers is usually linked to the program goal of avoiding or delaying nursing home admissions, thereby reducing the economic costs of care.

Services available under the Statewide Respite Care Program in New Jersey include:

- Companion Services
- Homemaker/Home Health Aides
- Temporary Out-of-Home Care in a Medical Facility
- Social Adult Day Care
- Adult Day Health Care

Adult Day Health Care is a coordinated program of health and social services provided in a home-like setting to elderly and frail adults with physical or mental impairments. Adult Day Health Care provides working caregivers with a positive, sensible and cost-effective community-based approach to caring for older adults with health limitations. Of equal importance, the support and respite offered by Adult Day Health Care enables working caregivers to be more healthy, productive employees.

Let me tell you about two families that have benefited from the Statewide Respite Program and Adult Day Health Care in particular.

Five years ago, Ellen's mother, Alice, was no longer able to take care of her own personal needs, shopping or cooking. Ellen felt that it would be best for her mother, Alice, to move in with her, as Ellen could be sure that she ate well, saw her physician when needed, and had the family to provide her with social stimulation. As the years past and Alice began showing signs of forgetfullness and increasing confusion, the new living arrangements became more difficult and stressful on the family, particularly Ellen. When Alice was admitted to the hospital for pneumonia, a social worker discussed with Ellen the increasing difficulties in caring for Alice at home. Ellen had been losing an increasing amount of time from her job and had even contemplated quitting. This would be a financial burden upon her and her family, but she felt she had no other recourse. Ellen did not want to place her mother in a nursing home but preferred to find some alternative types of care. She was referred to Barbara Wolfson, case manager for the Ocean County Statewide Respite Program.

Upon completing her assessment and evaluating the needs of the client and her family, it was agreed that Adult Day Health Care was the best level of service for Alice. Today she is attending Adult Day Health Care under the Statewide Respite Program. Ellen is now able to return to her job knowing her mother is at the Adult Day Health Care center and her needs are being met. Alice now looks forward to attending and spending time with her new friends. She also looks forward to coming home and talking about her day at the center. She no longer sits alone staring off into space, but is again a part of the family.

A second case history:

Ed and Ruth had lived in northern New Jersey in a two story home, when he began having episodes of falling. After seeing many physicians he was diagnosed with Multiple Sclerosis. He had only recently retired and was looking forward to their time together. They realized that there home would no longer be able to meet Ed's needs; so they bought a one level, ranch style home in a retirement village in Ocean County. Ed's physical condition deteriorated, he no longer was able to walk without a walker and began using a wheelchair for distances. He became incontinent of bladder and a foley catheter was inserted. He no longer went to the Clubhouse with his spouse or friends and became reclusive. Ruth would not leave him at home alone, and she also began to become isolated from her friends and the things that she enjoyed. While reading the local newspaper, she saw an article about Independence Place, Adult Day Health Care. She felt that this type of program might benefit both Ed and herself. She contacted the Program Director and after the evaluation process was completed, a referral was made to Barbara Wolfson, case manager for the Statewide Respite Program. Ed now attends the Adult Day Health Care program and has met another gentleman who lives down the street from him. Tony, who had a stroke and uses an electric wheelchair, and Ed are making plans for when the weather is warmer and they will ber able to spend time together outside. They no longer feel uncomfortable about their disability and their self esteem has increased. Ruth is again able to attend her meetings at the Clubhouse and have her own "space." She feels the time apart from each other has strengthened their relationship and helps them both with coping with Ed's increasing deterioration. She has peace of mind while he is at the center. Their, a registered nurse monitors his health and medical needs.

The overall goal of adult day care is to promote the independence of the older person to the highest degree possible. Day care is a structured program of coordinated social and health-related services in a protective setting during any part of a day but less than 24 hour care. Providing direct care and supervision, this program addresses individual client needs and is oriented towards prevention, maintenance and/or rehabilitation of persons who, due to physical, social, and/or mental impairment, require community based supportive services to prevent, delay or shorten institutionalization.

Individuals who participate in adult day care attend on a planned basis during specified hours. Adult day care assists it participants to remain in the community, enabling families and other caregivers to continue caring for an impaired member at home.

The National Institute on Adult Day Care presents the following goals for day care centers:

- Promote the individual's maximum level of independence.
- Maintain the individual's present level of functioning as long as possible, preventing or delaying further deterioration.
- Restore and rehabilitate the individual to his/her highest possible level of functioning.
- Provide support, respite and education for families and other caregivers.
- Foster socialization and peer interaction.
- Serve as an integral part of the community service network and the long-term care continuum.

Typical services of Adult Day Health Care programs are:

Provide or arrange transportation (handicapped

- In consultation with the client, the client's physician, family member or guardian, or other responsible individual, and the multipdisciplinary day care team, development of a specific client day care plan and goals appropriate to the client's individual functioning status and limitations.
- Nursing services including, but not limited to, evaluation of the client's needs, routine health monitoring and supervision and/or administration of medication.
- Assistance, as needed, with activities of daily living, walking, eating, toileting and personal care.
- A daily meal and supplementing snacks meeting one-third of the Adult Dietary Allowance.
- An activity program including: reality orientation (activities designed to promote the client's awarness of time, space, objects and persons); re-socialization and stimualtion (activities to encourage and assist clients to interact with staff and other clients); and supportive counseling (active listening, attention to expressed client's needs and suggestions, and guidance to promote interactions with others).

- Social services to clients and families, including psychosocial counseling, information and referral.

Adult Day Health Care is much more than a place where someone watches over the old folks. Every activity, service, and experience of each day is planned to achieve a specific purpose and is used to work toward the overall goals of care. Every action in which participants are involved, from time of leaving home to returning in the afternoon, is considered a part of the daily program. Traveling to and from the center, sharing meals, conversations, and other unstructured time are experiences which are considered program events, in that they are valuable time for socialization, skill renewal and development.

Adult Day Health centers offer a special place for day time care of adults who need professional supervision, but who do not need 24-hour institutional care. They offer fun, friendship, and acceptance to frail or disabled persons who might otherwise be isolated with their problems.

Day care programs provide therapeutic recreation for clients, while offering caregivers a respite, an interval of rest or relief from their taxing duties. By giving people with Alzheimers Disease or other physical problems a nurturing, safe place to socialize and engage in activities, day care programs help patients overcome feelings of poor self-esteem and depression. The isolation, unvarying routine and relative lack of stimulation that clients experience at home can add to their cognitive and behavioral difficulties. The carefully planned activities of Adult Day Health programs maximize the client's ability to function, helping to maintain both sense of self and self-esteem.

Health professionals have become increasingly concerned that the stresses experienced in caring for a disabled family member may erode the capacity of families to continue providing needed services. Family caregivers may be over burdened and severely distressed. Spouses may be at a greater risk of burden and distress because they are elderly themselves and are likely to have diminished physical capacity for demanding caregiving. Alzheimer's Disease and the related dementia disorders are thought to be particularly distressing to caregivers by virtue of the behavior disorders and rapid decreases in functional capacities of their family member. Adult Day Health centers provide families and others with assistance, support, and relief from the demands of constant caregiving as well as help cognitively impaired older adults to maintain their level of functioning and enhance their quality of life.

As the Director of an Adult Day Health center, I have found that the Statewide Respite Care Program has increased caregivers' quality of life, reduced the economic burden upon caregivers', enables working caregivers to be more healthy, productive employees, and, most importantly, assists cognitively and physically impaired older adults maintain their maximum level of functioning. Without the Statewide Respite Program, many of these families would not be able to obtain the much needed services that are available under this program. Your elderly caregiver would become physically and emotionally drained and very possibly become ill. Instead of one frail elderly person, we now would have two, both in need of care. In Ocean County the cost for a live-in, 24 hour home health aide averages $125.00 a day, weekends are higher. If you do not need 24 hour care but desire to purchase hourly service, that cost averages between $12.50 to $14.50. If a higher level of care is needed, which can only be obtained in a nursing home, the cost in Ocean County averages $110.00 a day, that is room and board only, not including ancillary services. Most families would very quickly go through there savings and would have to apply for public assistance, Medicaid. This would place increasing demand upon an already over-burdened state budget. Adult Day Health Care is cost effective and has proven to prolong community residence.

FRAIL ELDERLY OR DISABLED PERSON.....CAREGIVER.....

STATEWIDE RESPITE CARE PROGRAM

IT WORKS

Mary Jane Kegelman, M.S.W.

Senator **Bradley**. Thank you very much, Ms. Kegelman, for your testimony and also for your endorsement of S. 524.

Ms. **Kegelman**. Go for it.

Senator **Bradley**. That is a bill that is pending. I have introduced it, and it will be one of the things I will be working to get passed. I think your testimony will not only be helpful in trying to extend the New Jersey Respite Care Program, but I will also use it, if you don't mind, in my efforts to pass the bill for 100 days of adult day care.

Ms. **Kegelman**. Thank you. Be my guest, please.

Senator **Bradley**. Barbara Vandenberge, welcome to the committee.

STATEMENT OF BARBARA VANDENBERGE, EXECUTIVE ASSISTANT TO THE DIRECTOR, VISITING HOMEMAKER SERVICE OF OCEAN COUNTY

Ms. **Vandenberge**. Thank you very much.

I was very pleased to hear many references made earlier to the Visiting Homemaker Service and to the home health aides that are employed by us. For almost a quarter of a century the Visiting Homemaker Service of Ocean County has been providing homemaker/home health aide services, and yet many people really don't understand what a homemaker/home health aide is, so I would like to take a moment to try to illuminate that area.

By our standards and the standards of the National HomeCaring Council, which accredits us, a homemaker/home health aide is a paraprofessional who has successfully completed a State-approved training course, is certified by the State of New Jersey, and works as part of a home care team under the supervision of a registered nurse or social worker.

I would like to mention briefly that the Visiting Homemaker Service also operates a social day care program for adults with Alzheimer's Disease and related memory disorders. However, my focus here today is on the homemaker/home health aide, who traditionally has provided services in people's homes.

We have heard a lot of references here today about the kinds of needs that arise when an individual becomes frail or disabled or ill. I see it as being a spectrum. At one end of that spectrum we have two aspirin and a bowl of chicken soup. If it never went beyond that, we'd all be very happy and not need to be here today. At the other end of that spectrum is the professional care of doctors and nurses, hospitalization, and sometimes nursing home care.

There was a time when there wasn't a whole lot in between the two ends. Life expectancy was much shorter, and we basically lived and functioned independently, or we became ill and we died. Today, because life expectancy is longer, our old age is longer and we are living for a much longer period in the middle of that spectrum. The needs that arise all along that spectrum are things that we refer to as personal care and the activities of daily living. These are things that Mary Jane made reference to: assistance with bathing; grooming; getting in and out of a wheelchair; going to the bathroom; getting dressed; eating; fixing a meal; following a special diet; remembering to take medication; grocery shopping; straightening up—a million and one different things that we all take for granted until we can't do them anymore.

These are the needs that the homemaker/home health aide fulfills. The demand for someone to fulfill those needs is, as a result, becoming greater every day.

The role of the homemaker/home health aide in the provision of respite care is a pivotal one, but in order to really understand that role, there is something in addition to the actual duties that are performed that we need to understand clearly, and that is the human factor. That is a lot harder to explain. What motivates someone to become a homemaker/home health aide, and what are the qualities that go into making that person so special in the lives of the people they're taking care of and the family members?

So why does someone become a homemaker/home health aide? I can assure you that it's not for the money. The hours are not great. The work can be very difficult. The benefits were nonexistent until recently. It can be a thankless job. On top of that, all homemaker/home health aides are required to attend continuous educational programs to reinforce and upgrade their skills without pay. So you may wonder why anyone would even consider becoming a homemaker/home health aide.

Just recently I ran into an aide that I had met a few years ago. She was telling me about her patient, who is 103 years old. I could see something in her eyes, kind of a little light. I remembered that I was going to be coming here today, and I asked her, "Antoinette, tell me what it is that you like so much about being an aide." She said, "Well, you know, I lost my parents when I was 5 years old. In taking care of Helen, I have the chance to give her the love that I couldn't give my parents because I lost them when I was little." She didn't mention "the work's easy," or "she's a sweet old lady," or "I like going to visit her," no. She had love to give. Even though her particular circumstances may be unique, her feelings are not.

Our homemaker/home health aides for the most part have something that we can't teach them. They have something that can't be bought, something that can't be written into a plan of care or prescribed by a doctor. They have love. Although that may seem a little corny to some people, I see the result of it every day. These are people who have a basic love of people and a desire to be of service. They are nurturers, people who need to be needed. We can teach them procedures, we can teach them regulations, we can teach them all the things the State says they have to know in order to do that they do, but if they didn't have the life skills and that basic, caring, gentle hand, they wouldn't be nearly as effective as they are, and we can't give them that. They've got that.

We recently did a survey of some of our homemaker/home health aides and asked them about the work that they do. I would like to share with you some of their responses.

Muriel Galloway told us, "The most important part of my job is caring for my patients, helping them feel better, making them more comfortable, sharing their worries and concerns. Sometimes I help with paperwork, bills, or things that they don't understand or don't want to understand, but it's important to them."

Sara Ann Durante said, "It is such a great feeling knowing that you have helped someone and made them feel that you really care about them and that they are wanted and loved, too."

Luanne Mazzara offered, "To be able to work with patients in their own homes and the joy in seeing them get well and the happiness which I can give them—this in turn makes me feel good about myself."

Muriel Wilkens told us, "I enjoy working with elderly people. Some are very lonely. They look forward to seeing someone come to visit. Some would not be able to stay in their homes if they did not have a homemaker/home health aide."

And finally, Doris Crean said, "Most important is keeping people in their own homes. I had a patient who died in my arms. She was having seizures and we knew it was almost the end. She was so scared. I lay on the bed and took her in my arms. She snuggled close, said 'I love you,' and passed away."

But as you've heard here today, the patients aren't the only ones that are touched by the special brand of caring that the homemaker/home health aide provides. The family caregivers, what happens to them as their loved ones' needs progress on that spectrum? The husbands, the wives, the children, the parents, the friends, what happens to them? Where do they go?

You have heard quite a bit today, so I don't want to repeat too much of what you have already heard, but it is important to understand that eventually, fulfilling the needs of the loved one becomes all-consuming, not only taking up time, but taking up the caregiver's life until you have two people living one existence, the existence of the loved one in need. It is an existence that is held together by an exaggerated sense of loyalty, obligation, and sometimes guilt, and it is an existence that leaves no room for anything but survival. No room for laughter, love, hope, nothing but day-to-day, minute-to-minute survival. It is an existence that can and sometimes does lead to abuse as the caregiver struggles with the instinctual desire to live his or her own life. It can and often does lead to the illness or even death of the caregiver as they succumb to the awesome responsibility that is on their shoulders.

But introduce a homemaker/home health aide like Muriel Wilkens or Doris Crean to their lives, and you create room for laughter and love to return. You create time for the caregiver to live a life, not to share an existence.

Home care has become a major industry in this country. For many, it is a big business. For most of us it is still a human service, and for a human service to remain truly human it has to have a heart. We at the Visiting Homemaker Service believe very strongly and without any doubt that the homemaker/home health aide is truly the heart of home care. For that heart to keep beating, bringing life to the frail elderly, ill and disabled men and women and children of New Jersey, we must have the continued support of the public and the officials who represent them.

[The prepared statement of Ms. Vandenberge follows:]

VISITING HOMEMAKER SERVICE
OF OCEAN COUNTY, INC.
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TESTIMONY FOR VISITING HOMEMAKER SERVICE OF OCEAN COUNTY, INC.
SENATE SUB-COMMITTEE PUBLIC HEARING
MONDAY, APRIL 16, 1990

For nearly a quarter of a century, the Visiting Homemaker Service has been providing Homemaker-Home Health Aide services to the people of Ocean County during times when illness, aging or disability threaten their chances of remaining safely and comfortably in their homes. The Homemaker-Home Health Aide's role in the provision of respite care is a pivotal one. But to understand that role, we must first understand exactly what a Homemaker-Home Health is...and what she is not.

A Homemaker-Home Health Aide is NOT a nurse. She is also NOT a domestic. By our standards and the standards of the National HomeCaring Council which accredits us, a Homemaker-Home Health Aide is a para-professional who has successfully completed a state-approved training course, is certified by the State of New Jersey and works as part of a home care team under the supervision of a Registered Nurse or Social Worker.

If we look at the needs which arise from illness, aging and disability, we see a spectrum. At one end of the spectrum, we have "two aspirin and a bowl of chicken soup." At the other end of the spectrum, we have hospitalization and the professional care of doctors and nurses. There was, perhaps, a time when there was not much in between because human life expectancy was short and we basically lived and functioned independently or we became ill or injured and died. And if we did find ourselves briefly in the middle of that spectrum, our families took care of us or we went into a nursing home.

That is not the case today. The two ends of that spectrum have grown further apart and the vast majority of men and women whose lives are being affected by illness, aging or disability have needs that fall somewhere in between. What they need is assistance with personal care and the activities of daily living; help with bathing, grooming, toileting, getting dressed, remembering to take their medicine, doing exercises that may have been prescribed by a therapist, getting in and out of bed or a wheelchair, using a walker, planning and preparing meals, following a special diet, grocery shopping, doing laundry,...a hundred different things that are essential to living life but that become increasingly difficult for more and more people each day, things that most of us take for granted unless we cannot do them. These are the needs that a Homemaker-Home Health Aide fulfills.

So the role of the Homemaker-Home Health Aide in the provision of respite services becomes clearer. But there is another factor that we must understand before we can clearly comprehend the impact of her role. That factor is not as simple to explain because it is the human factor, the personal qualities that motivate someone to become a Homemaker-Home Health Aide and make them special in the lives of the people they serve.

So, why does someone become a Homemaker-Home Health Aide? I can assure you that is is NOT for the money. The hours are not steady, the benefits until recently were non-existent, the work is hard and it can be a thankless job. In addition, Homemaker-Home Health Aides are expected to devote some of their free time to on-going educational programs to continuously reinforce and upgrade their skills, without pay.

So why, in view of all of this would anyone even consider becoming a Homemaker-Home Health Aide?

One aide told me recently that she had lost her parents when she was five years old and that caring for her elderly patients was her way of giving the love that she would have liked to have given to them. Though her experience is uncommon, her feelings are not. Our Homemaker-Home Health Aides are not simply workers who are assigned to cases. They bring with them something that cannot be taught in a classroom, that cannot be bought, that cannot be written into a plan of care or prescribed by a doctor. They bring a deeply rooted and basic love of people. They are nurturers who need to be needed, women...and men, too...who have a desire to be of service to others. They usually lack formal education but more than make up for that with an abundance of "life skills." We may teach them techniques and procedures, but the caring, gentle hand is uniquely theirs.

In a recent, informal survey of some of our aides, we asked them about their work. I would like to share with you some of their responses.

Muriel Galloway told us, "the most important part of my job is caring for my patients, helping them feel better, making them more comfortable, sharing their worries and concerns. Sometimes I help with paperwork, bills or things they don't understand...or don't want to understand, but it's important to them."

Sara Ann Durante said, "it is such a great feeling knowing that you have helped someone and made them feel that you really care about them and that they are wanted and loved too."

Luanne Mazzara offered, "to be able to work with patients in their own home and the joy in seeing them get well and the happiness which I can give them...this in turn makes me feel good about myself."

Muriel Wilkens told us, "I enjoy working with elderly people. Some are very lonely. They look forward to seeing someone come to visit. Some would not be able to stay in their home if they did not have a Homemaker-Home Health Aide."

Doris Crean said, "most important is keeping people in their own homes. I had a patient who died in my arms. She was having seizures and we knew it was almost the end. She was so scared. I lay on the bed and took her in my arms. She snuggled close, said, "I love you," and passed away."

The patients are not the only ones whose lives are touched by the special brand of caring that the Homemaker-Home Health Aide provides. The family caregivers, the husbands or wives or children or friends who may be there in the beginning to dispense the aspirin and make the chicken soup - what happens to them as their loved one's needs progress on the spectrum? Eventually, fulfilling those needs takes precedence over all else, including their own needs. It becomes an all-consuming, twenty-four hour a day, seven days a week job. It takes over not only the caregiver's time...it takes over their life until you have two people living a single existence, the existence of the loved one in need. It is an existence held together by an exaggerated sense of loyalty, obligation and guilt and it is an existence that has no room for anything but survival - no laughter, no love, no hope - just day-to-day, minute-to-minute survival. It can and occasionally leads to abuse as the caregiver struggles with the instinctual desire to live his or her own life. And it can and often does lead to the illness or even death of the caregiver who has succumbed to the awesome responsibilities.

But introduce a Homemaker-Home Health Aide like Doris Crean or Muriel Wilkens to their lives and you create room for laughter and love to return. You create time for the caregiver to live a life, not share an existence.

Home Care has become a major industry in this country - a big business for many. But is is still, for most of us, a human service. For any human service to remain truly human, it has to have a heart, and we, at the Visiting Homemaker Service of Ocean County, believe without any doubt, that the Homemaker-Home Health Aide is truly the heart of home care. For that heart to keep beating, bringing life to the frail elderly, ill and disabled men and women of New Jersey, we need the continued support of the public and the officials who represent them.

Barbara Vandenberge

Barbara Vandenberge
Executive Assistant

Senator BRADLEY. Let me thank all three of you for your moving testimony. The first panel were the caregivers and the recipients of respite care, and you all are the providers.

I just want to ask one question, and that may be best addressed to Mary Fran McFadden.

How many facilities do you serve in Ocean County through the Respite Care Program?

Ms. MCFADDEN. The funding that we received allows us to provide service to a minimum of 92 people.

Senator BRADLEY. Ninety-two. What would you say the unmet need is?

Ms. MCFADDEN. I think I could easily say 10 times that much.

Senator BRADLEY. Ten times? So it is at least a thousand. Well, I think that that indicates one of the major issues.

Also, on home care, right now Medicare covers 21 days of home care, and that's woefully insufficient. We hope we will be able to increase that, maybe double it. Your stories, I think, will be an important part of our ability to do that.

Any time there is a human need that is being met, but perhaps only up to 10 percent of the human need, you are not meeting the human need. So each of you has given eloquent testimony—Mary Fran McFadden—to the need for reauthorizing the New Jersey Respite Care Program, at least, and then going to a National Respite Care Program; Many Jane Kegelman, to the importance of adult day care; and Barbara Vandenberge, to an eloquent and moving statement, I think, on the importance of home care.

I want to thank all three of you very much for sharing your views with the committee.

I noticed you had your microphone ready, Ms. Vandenberge. Did you want to say something?

Ms. VANDENBERGE. Just simply that I think everyone would agree with me—at least I hope they would—that one of the problems in the past has been in the Government's effort to make our health care provision more economical. Many, many times belts have been tightened, but what has unfortunately been neglected, except by you, Senator Bradley, is the idea that home care is not part of the problem. It is, in fact, the solution to the problem. Only by giving it the recognition and the support that it deserves will we ever really be able to adequately meet the health care needs of our society.

Senator BRADLEY. Thank you very much for your last comment, with which I obviously agree.

Let me thank all three of you for your informative and powerful testimony.

Our last panel today moves from the beneficiaries and caregivers and the providers to those other interested parties. We are very fortunate today to have testifying Alan J. Gibbs, who is the Commissioner of Human Services for the State of New Jersey and someone who has a very large responsibility.

Welcome to the committee, Mr. Gibbs, and congratulations on your new job.

Mr. GIBBS. Thank you, Senator. I appreciate it.

Senator Bradley. And then we have Dudley Lesser, who is the VOTE State Coordinator for the New Jersey Chapter of the American Association of Retired Persons.

Mr. Lesser, welcome to the committee.

And Ruth Boer, who is the Past President of the Home Health Assembly.

Commissioner Gibbs, the microphone is yours. Thank you again for taking the time to come to this hearing. I think it indicates your own personal interest. I know that you are very busy. You have a lot to administer, and I think it means a lot to the senior citizens of New Jersey and to me personally that you would come to our hearing today. Thank you.

STATEMENT OF ALAN J. GIBBS, COMMISSIONER OF HUMAN SERVICES, STATE OF NEW JERSEY

Mr. Gibbs. Thank you, Senator. I am delighted to be here.

I am pleased to be here to testify about a real success story about human services in New Jersey, and that success story simply is the Respite Care Program. As a result of this program we are finding that families are better able to care for their elderly and disabled relatives, that institutionalization is being prevented or delayed, that family caregivers themselves are able to seek the medical care that they need, knowing that their loved ones are being cared for, that caregivers are experiencing lower stress levels, that married couples and families report that their relationships with each other have improved because they are receiving help to care for their elderly or disabled relatives.

We have served 1,900 families statewide in this program, and there are waiting lists in one quarter of our counties. Each month we serve about 1,200 families across the State.

Clearly, respite care is a much-needed program, and that's not just my opinion. The authors of the current best-seller, Megatrends 2000, cite elder care as one of the major directions of the 1990's. They report that almost one-third of all working adults are responsible for providing some care for an elderly person. In New Jersey, that's about 1.2 million people.

Thanks to your help, Senator, we have been one of the few States that have been able to begin to meet this need for services, and we are the only State that is authorized to run this demonstration project. Because of your leadership, New Jersey ranks ahead of the Nation in providing respite care services.

We strongly support your introducing legislation to extend this Federal demonstration that expires this year, and to authorize another $2 million in Federal funds to continue to provide these critical services. As tight as the State budget is, Governor Florio has seen to it that the State match is available in the budget for next year.

Respite care is but one of several community-based services that New Jersey provides to the elderly and disabled. We also provide home health care, medical day care, and personal care assistance services. The total annual cost of these services is estimated at $87 million.

This year we were able to expand one of our other model waivers as a result of legislation you sponsored to increase the limit on the number of persons who could be served. That program allows mostly children to be cared for in the home rather than in the more costly hospital.

We are learning what works and what doesn't work in reducing the need for institutional care. Our system can expand to provide these services as an alternative to institutionalization, provided that there is sufficient Federal support. Quite simply, alternatives to institutional care usually cost less, are more humane, and more often, more effective than a hospital or nursing home. While the Federal Government provides almost unlimited funds for institutional care, many of the programs offering alternative care are capped. These programs include the Model Waiver Program, that I mentioned before; the AIDS Waiver; and the Community-Based Waivers for the Elderly and Disabled.

We have all the waivers we need. What we want is for the Federal Government to recognize that community-based care is not a luxury. It is a necessity, and it must become more available.

Your bill, the Medicare Home Benefits Improvement Act of 1990, would move the Nation further in the right direction. It would provide an additional 80 hours of in-home respite care, increasing nursing and homemaker/home health aide services, expand hospice benefits, and provide home intravenous drug therapy. We know from our experiences in New Jersey that these services will result in fewer families having to deplete their savings in order to make their loved ones eligible for nursing homes. It will also foster greater independence for the elderly and disabled.

It would do all of this as an entitlement under Medicare. It would not require the State to apply for lengthy waiver applications or appropriate additional State funds. It would not place a limit on how many persons could receive those services.

In 1988, home health care represented only 2 percent of the Medicare budget. Your bill would begin to more realistically address the need for community-based care nationwide.

Now, we will face some initial costs to expand community-based care while we reduce institutional care. Let me offer two suggestions about how we might find the resources to assume these costs.

First, the Federal Government must allow States the flexibility they need to make the Medicaid Program more efficient, while maintaining quality care. The Medicaid budget in New Jersey, which is currently about $2 billion a year, is escalating at a rapid rate that is robbing us of our ability to develop new initiatives for other human services programs. Greater cost containment is possible in this program, but we need to help to cut through the red tape in Washington. For example, we need greater emphasis at the Federal level for managed medical care, such as through health maintenance organizations. Thanks to your legislative efforts, the Garden State Health Plan is now the first State-run HMO in the Nation recognized by the Federal Government.

Second, we need to set some new priorities nationally. The recent dramatic changes in Eastern Europe and the USSR may lead to significant arms reductions, enabling us to direct more of our scarce resources to address major national needs, such as health care.

In conclusion, Senator, it has been said that a journey of a thousand miles begins with but one step. Because of your vision and leadership, that step has been taken in New Jersey. We look forward to working with you to complete this journey, which will end only when every elderly and disabled person can receive the care they need with dignity, compassion, and hope.

Thank you.

Senator BRADLEY. Thank you very much, Commissioner, for coming to the committee today. We will go through the rest of the panel and then I will ask a few questions. I appreciate your support of the bills that you have enumerated.

Mr. Lesser.

STATEMENT OF DUDLEY LESSER, NEW JERSEY STATE COORDINATOR FOR AARP/VOTE, AMERICAN ASSOCIATION OF RETIRED PERSONS

Mr. LESSER. I am pleased to be here this afternoon on behalf of the American Association of Retired Persons to discuss the need for respite care and the other important benefits included in the Medicare Home Benefits Improvements Act of 1990.

AARP commends you, Senator Bradley, for your efforts to focus attention on the continuing need for Medicare coverage of long-term care services. In this regard, we applaud your leadership in the development and enactment of a respite care benefit as part of the Medicare Catastrophic Coverage legislation. It is our hope that with your help we will see the reinstatement of a respite benefit.

My remarks today center on three areas: one, the effect of rising health care costs on older Americans' ability to obtain needed health care; two, the importance of the four new and expanded benefits included in S. 2246—respite care, home IV therapy, and expanded coverage of both home health care and hospice care; and three, financing these proposed new benefits.

To understand fully how important Medicare coverage of these benefits is, it is necessary to look how increasing health care costs have widened the gaps in Medicare's protection of older beneficiaries.

When it was created in 1965, Medicare dramatically increased access to acute health care services and reduced out-of-pocket medical expenses for most elderly people. But over the years, rising health care costs have gradually widened the gaps in Medicare's protection. Beneficiaries are faced with higher deductibles and co-insurance for services covered by Medicare, as well as increased costs for necessary services not currently covered by the program. In many cases these escalating costs have created insurmountable financial barriers to essential medical services.

Coverage of the services included in your legislation is a small but important step toward closing these gaps in Medicare protection. Let me briefly explain why.

A Medicare respite benefit, although limited in nature, is an important step toward long-term care and is the type of support service that caregivers most frequently want and need, as we heard today. Right now, fewer than one in five older Americans who need long-term care are in nursing homes. Most of these people remain in their communities and depend on families and friends for their care. The burdens on those who provide informal long-term care, both financial and emotional, are tremendous.

The ability to take a needed break from caregiving, secure in the knowledge that a loved one is well-attended, will significantly reduce the burden on these caregivers.

Your efforts to extend the New Jersey Respite Care Program are to be commended. From a policy perspective, experience with a small-scale respite benefit can provide critical information which will be essential to the future development of a more comprehensive long-term benefit.

While demonstration projects like the one here in New Jersey are extremely valuable, AARP believes that respite care is needed on a much broader scale so that caregivers nationwide can enjoy the important benefits currently found in the Garden State.

The extension and clarification of the Medicare home health care benefit in S. 2246 is also an important step toward simplifying Medicare. Current law limits the scope and accessability of Medicare home health coverage. This limitation has stemmed both from strict eligibility requirements and inconsistency in the interpretation of the definition of "intermittent care." This legislation helps to clarify the definition of intermittent care and, in doing so, ensures that beneficiaries will now have a greater access to the home care that they most need.

AARP is also pleased that S. 2246 provides Medicare coverage of home intravenous drug therapy. While this expanded Medicare coverage of prescription drugs is very narrowly defined, it is a step in the right direction. Prescription drug prices continue to increase. Between 1980 and 1989, prescription drug prices rose by 128 percent, compared with an increase in the overall Consumer Price Index of just over 50 percent. Medicare coverage of home IV therapy will begin to ease this burden for some older Americans by enabling beneficiaries to receive treatment that might be more cost-effectively provided in the home, the setting they prefer.

Finally, the expansion of the Medicare hospice benefit beyond the current 210-day limit will ensure that terminally ill Medicare beneficiaries can continue this unique form of care without interruption and without loss of self-respect or dignity.

S. 2246 proposes to finance these new and expanded benefits through an increase in the monthly Part B premium paid by beneficiaries, estimated to be from $0.55 the first year, and rising to $1.57 in the fifth year. It is the intent of the bill to generate enough revenue to cover the estimated cost of the four new and expanded Medicare benefits.

Beneficiary-only financing is not what AARP would want to see used for future benefit expansion. The Association views the additional financing of Medicare Part B, which spreads the costs of the program across the entire population, as the fundamental tenet of the Medicare Program, which should not be breached lightly. Any revenue shortfall which might occur as the result of such financing should be offset by income from such sources as increased tobacco taxes, or inclusion of all State and local workers in Medicare.

As AARP weighs the importance of these benefits against concerns about Medicare beneficiaries' ability to shoulder this increased financial burden now and in the future, the premium-only financing in this act is an extraordinary step that is acceptable only in the short term, given the imperatives of Gramm-Rudman requirements, and only because the premium increase in this case is so small. We believe that these benefits should ultimately be financed in the same manner as other Medicare benefits. Should the cost of the benefits of this act—and therefore, the premiums—rise very much at all, the Association would need to reevaluate its position on this delicate balance of benefits and financing.

In conclusion, I would like to say that AARP applauds your efforts to restore four critically important Medicare benefits. We appreciate the opportunity to share our views with you on this legislation and look forward to continuing to work with you on improving the Medicare Program.

Thank you.

[The prepared statement of Mr. Lesser follows:]

STATEMENT
of the
AMERICAN ASSOCIATION OF RETIRED PERSONS

Introduction

Good afternoon. My name is Dudley Lesser. I am the New Jersey State Coordinator for AARP/VOTE. I am pleased to be here this afternoon on behalf of the American Association of Retired Persons to discuss the need for respite care and the other important benefits included in the Medicare Home Benefits Improvements Act of 1990.

AARP commends you, Senator Bradley, for your efforts to focus attention on the continuing need for Medicare coverage of long-term care services. In this regard, we applaud your leadership in the development and enactment of a respite care benefit as part of the Medicare Catastrophic Coverage legislation. It is our hope that with your help we will see the reinstatement of a respite benefit for all Medicare beneficiaries in the near future.

My remarks today center on three areas: 1) the effect of rising health care costs on older American's ability to obtain needed health care; 2) the importance of the four new and expanded benefits included in S. 2246: respite care, home IV therapy and expanded coverage of both home health care and hospice care; and 3) financing these proposed new benefits.

Rising Health Care Costs

To fully understand how important Medicare coverage of respite care, home IV therapy, expanded home health care and hospice care is, it is necessary to look at how increasing health care costs have widened the gaps in Medicare's protection of older beneficiaries.

Medicare is the cornerstone of health care coverage for older Americans. Approximately 98 percent of the elderly are now covered by Part A - hospital insurance - and 97 percent pay the monthly premium for Part B coverage of physician and outpatient services.

When it was created in 1965, Medicare dramatically increased access to acute health care services and reduced out-of-pocket medical expenses for most elderly people. But over the years, the gaps in Medicare's protection have gradually widened. It is now estimated that older Americans spend about 15% of their yearly income on health care - roughly the same percentage they spent before Medicare was enacted.

Rising health care costs are largely responsible for this trend. In 1987, health care costs increased nearly ten percent over the preceding year. In 1989, price increases for physician services grew at roughly one and one-half times the rate of general inflation, while hospital price increases were more than double the general inflation rate.

These cost increases have had a direct effect on Medicare beneficiaries. In addition to increased Medicare premiums, they are faced with increased deductibles and coinsurance for services covered by Medicare as well as higher costs for necessary services - like respite care - not currently covered by the program. It is estimated that for every dollar beneficiaries spend on Medicare deductibles and coinsurance, they spend another fifty cents to one dollar on non-covered services. In many cases, these escalating costs have created insurmountable financial barriers to essential medical services.

The expansion of Medicare to provide the long-term care services included in the Medicare Home Benefits Improvement Act is a small but important step toward closing the gaps in Medicare's protection of the elderly.

The Need for Respite Care

AARP is very pleased that S. 2246 restores the Medicare respite benefit. Although the benefit included in this bill is limited in nature and will help substantially fewer beneficiaries than the respite care provision initially enacted into law, it is an important long-term care benefit and, as we heard today, is the type of support service caregivers want and need.

Currently, among older Americans who need long-term care services, fewer than one in five receive this care in a nursing home. The remainder continue to live in their communities and depend on a network of informal caregivers - usually family and friends - for their care. Roughly three-quarters of disabled older persons who are not in nursing homes depend solely on this type of informal care.

The burdens on those who provide informal long-term care--both financial and emotional--are tremendous. An informal caregiver survey conducted by the U.S. Department of Health and Human Services found that one third of family caregivers are over the age of 65 themselves. Many live in or near poverty and describe their own health as relatively poor. Others, notably women, must balance the competing demands of their own families with their caregiving responsibilities. Almost one-half of adult daughters providing care to older parents are employed outside the home, and one-quarter have children under the age of 18.

Real life situations where the availability of respite care services could mean the difference between continuation of the in-home care an elderly beneficiary prefers and institutionalization best tell the story.

In addition to the accounts we have heard today, there are hundreds of others which highlight similar needs - the wife of the Alzheimers patient in Michigan who, by herself, has cared for her husband for the past five years rather than placing him in a nursing home; the 69 year-old woman in Alabama who is the sole caregiver for her 93 year-old, severely incapacitated mother; and the husband of an Alzheimer patient in Maryland who has cared for his wife for the past thirteen years. For these people, and thousands of others like them, the ability to take a needed break from their caregiving, secure in the knowledge that their loved one is well attended, significantly reduces the burden of caregiving. The New Jersey respite care program is proof of this fact. Since 1988 this federal-state demonstration program has provided a range of respite care services to approximately 1200 families a year who care for relatives with functional or cognitive impairments.

Throughout twenty-one counties, many New Jersey residents who meet the eligibility requirements for the program are able to take advantage of homemaker and home health aide service, social and medical adult day care and limited inpatient respite care - all vital services that enable a person to balance their own needs and the needs of their family with their responsibility as a caregiver.

Your efforts to extend the New Jersey Respite Care program are to be commended. From a policy perspective, experience with a small scale respite benefit can provide critical information about issues such as administration, "gatekeeping," eligibility criteria, quality assurance, and cost information which will be essential to the future development of a more comprehensive long-term care benefit. It is our understanding that Rutgers University will be conducting a thorough study of the effectiveness of the New Jersey program - the results of which we hope will be useful as Congress considers respite care in a larger context.

While demonstration projects - like the one here in New Jersey - are extremely valuable, AARP believes that respite care is needed on a much broader scale so that caregivers nationwide can enjoy the important benefits currently found in the Garden State. It is the Association's hope that, when a respite benefit is incorporated into a more comprehensive national long-term care program, eligibility criteria that more accurately reflect the need for long-term care (i.e., measurements that reflect limitations in activities of daily living (ADLs) and in cognitive functioning), will replace the criteria in the Medicare Home Benefits Improvement Act. This will be important in ensuring that those Medicare beneficiaries with functional impairments--regardless of the cause--who most need this type of service are not precluded from coverage.

To ensure that program participants receive the most appropriate benefits and that the program remains affordable both to program participants and the government over the long term, it will also be important that program "gatekeepers" are not also service providers. Even with safeguards, like those in the New Jersey program, the potential for conflict of interest that results from this dual role should not be permitted in a larger scale program.

The Need for Expanded Home Health Care

The expansion and clarification of the Medicare home health benefit in S. 2246 is an important step toward simplifying Medicare. It will also ensure that the program provides a meaningful, though limited, home health benefit.

Current law limits the scope and accessibility of Medicare home health coverage. This limitation has stemmed from both strict eligibility requirements and an inconsistency in the interpretation of the definition of intermittent care. This legislation does not change the requirements that beneficiaries of the homecare benefit be homebound; under the care of a physician; in need of skilled care on an intermittent basis; or in need of physical or speech therapy. It does, however, help to clarify the definition of intermittent care.

The Health Care Financing Administration currently interprets "intermittent" to mean four days or less per week. As a result, beneficiaries who meet the standard eligibility criteria and require skilled home health care less than four days a week have qualified for Medicare coverage. But individuals who need skilled home health care more than four days a week are often denied coverage.

S. 2246 expands the Medicare home health benefit by clarifying the definition of intermittent to mean less than seven days a week. This means that beneficiaries could qualify for Medicare coverage of home health care if they meet the standard eligibility criteria and required skilled care on an intermittent basis for up to six days a week. The legislation also provides that beneficiaries needing care seven days a week may be covered for thirty-eight consecutive days. By expanding and clarifying the Medicare home health care benefit, beneficiaries will now have greater access to the home care they most need.

The Need for Home Intravenous Therapy

AARP is also pleased that S. 2246 provides Medicare coverage of home intravenous drug therapy. While this expanded Medicare coverage of prescription drugs is very narrowly defined, it is a step in the right direction. Prescription drug prices continue to increase. Between 1980 and 1989, prescription drug prices rose by 128 percent, compared with an increase in the overall Consumer Price Index (CPI) of just over 50 percent. In 1989 alone, when the overall rate of inflation was 4.8 percent, average prescription drug prices rose by 8.7 percent.

High prices, heavy utilization, and only limited coverage in the private Medigap market have converged to make prescription drugs the second highest out-of-pocket medical expense for older people. Medicare coverage of home IV therapy will begin to ease this burden for some older Americans.

Generally, when an elderly beneficiary suffers from a serious infection it requires long-term administration of antibiotics. This often results in prolonged or repeated hospitalizations and added hardship for the beneficiary.

With the advent of home IV therapy, some beneficiaries may now have antibiotics administered in the home setting they prefer - enabling them to avoid repeated hospitalizations and and maintain a more normal lifestyle. Currently, however, Medicare provides coverage for IV therapy only when it is administered in a hospital setting. That means that a beneficiary must enter the hospital for an extended period of time at a considerable cost to Medicare to receive a treatment that might be more cost-effectively provided in the home. Medicare coverage of home IV therapy would enable Medicare beneficiaries to receive the care they require in the home-based setting they prefer.

We are pleased to note that your legislation also directs the Prospective Payment Assessment Commission to study the financial effect that this provision could have on hospital discharges. We would also encourage that this provision be accompanied by the reinstatement of a Congressional Commission to monitor the cost of prescription drugs and pricing trends.

The Need for Expanded Hospice Care

The Medicare hospice benefit has, for the past several years, provided terminally ill beneficiaries with a unique and valuable form of care unavailable in most other settings. The primary focus of hospice care is to ensure optimal comfort and enhance the quality of life for terminally ill beneficiaries and their families.

In order to qualify for Medicare coverage of hospice care, a physician must certify that the beneficiary has less than six months to live. After a beneficiary qualifies, Medicare currently covers only 210 days of hospice care. It is not uncommon, however, for a terminally ill patient to live beyond the 210-day limit. Yet, in the case of Medicare, coverage of hospice care ceases after 210 days and the beneficiary or the hospice is then responsible for the remaining costs of his or her care. Expansion of the 210-day limit will ensure that terminally ill Medicare beneficiaries can continue - without interruption - this unique form of care.

Financing

S. 2246 proposes to finance these new and expanded benefits through an increase in the monthly Part B premium paid by beneficiaries--estimated to be from eighty-cents to $1.00 the first year and rising to $1.30 in the fifth year. It is the intent of the bill to generate enough revenue to cover the estimated costs of the four new and expanded Medicare benefits.

It has long been the Association's policy that the federal budget deficit be brought under control so that our children and grandchildren are not left with an overwhelming financial debt.

And from the standpoint that this legislation attempts to finance these needed Medicare benefits without adding to the federal deficit, you are to be commended. The Association is concerned however, about the unpredictability of health care costs and the effect that this continues to have on Medicare beneficiary out-of-pocket costs.

Currently, Medicare beneficiaries are required to pay twenty-five percent of Part B program costs. As health care costs have continued to escalate, this requirement has resulted in a substantial out-of-pocket burden for the elderly. In 1988, older Americans spent over $13 billion on Medicare's deductible and coinsurance requirements - up 180 percent from 1980. In 1988 Medicare beneficiaries also paid over $8 billion in Part B premiums. This was in addition to the over $16 billion paid for private supplemental insurance and the additional costs for needed services not covered by Medicare.

It should come as no surprise that, given the course of activities over the last several years, beneficiary-only financing is not what AARP would want to see used for future benefit expansions. The Association views the traditional financing of Medicare Part B--which spreads the cost of the program across the entire population--as a fundamental tenant of the Medicare program which should not be breached lightly. Any revenue shortfall which might occur as a result of such financing should be offset by income from such sources as increased tobacco taxes or inclusion of all state and local workers in Medicare.

However, improvements to Medicare provided by this legislation are very important to older Americans and the response from our own membership reinforces this.

As AARP weighs the importance of these benefits against concerns about Medicare beneficiaries' ability to shoulder this increased financial burden now and in the future, the premium-only financing in this Act is an extraordinary step that is acceptable only in the short term - given the imperatives of Gramm-Rudman requirements - and only because the premium increase in this case is so small. Ultimately, we believe that these benefits should be financed in the same manner as other Medicare benefits. We would also note that should the cost of the benefits in this Act- and therefore the premium - rise very much at all, the Association would need to reevaluate its position on this delicate balance of benefits and financing.

Conclusion

In conclusion, I would like to say that AARP applauds your efforts to restore four critically important Medicare benefits. The current public policy debate over health care during the last several years has framed some new questions and challenges. While in some respects this nation's health care system is among the best in the world, many Americans--old and young--are not getting the kind of care they need when they need it. This is not made any easier by the fact that there is no way of knowing when a person is going to need a certain kind of care--whether it be physician or hospital services, preventive care, prescription drugs or long-term care.

What is clear, however, is that the rising costs of health care stands out as the most significant obstacle to obtaining affordable, appropriate and quality health care. We cannot address cost and the other shortcomings of our health care system in a piecemeal fashion. The real answers to these problems can only come if we view each of these concerns as part and parcel of a concerted effort to make health care--whatever its form--affordable and available to all Americans, young and old.

We appreciate the opportunity to share our views on S. 2246 and look forward to continuing to work with you on improving the Medicare program.

Senator BRADLEY. Thank you very much, Mr. Lesser, for your testimony.

Now, Ms. Boer, welcome to the committee. I am pleased that you came all the way down from Hackensack for the hearing.

Ms. BOER. Thank you.

Senator BRADLEY. I had the chance to visit one of the adult day care centers in Bergen County. It was my first contact with the importance of such facilities for the families of Alzheimer's patients. It was really that visit that led to my introduction of the adult day care bill.

STATEMENT OF RUTH BOER, PAST PRESIDENT, HOME HEALTH ASSEMBLY OF NEW JERSEY

Ms. BOER. I represent the Home Health Assembly of New Jersey, which is the statewide nonprofit association of home health care providers. As the Senator says, I am also the administrator of a home health agency, providing home care services.

When you say that Medicare started in 1965, I kind of took a deep breath because I was there at this agency when it started.

I am here today to speak to you on behalf of the 100 home health agency members of the Assembly. Together, these agencies provide in-home services to over 150,000 patients residing in every city and town in New Jersey. About three-quarters of these patients are over 65 years of age.

I would like to highlight some of the important changes that have taken place in home health care over the past few years and outline what we in the home health industry see as the unfinished agenda in caring for patients at home.

Home health care services are the backbone of the effort to help family members cope with caring for their elderly relatives. That was said so eloquently so many times already. Eighty percent of all respite care now is home-based care of one kind or another.

The demonstration program that has been described here is crucially important because it helps address two major trends which are on a collision course. First, as you all know, we are seeing a rapid growth in the number of the very old, those over the age of 75. In fact, only Florida has a population older than New Jersey's.

The second trend really has a direct impact on the first. Today, over 70 percent of women between the ages of 35 and 54 are employed outside the home. This means that there are far fewer women—we are still the traditional caregivers for the elderly—at home to take care of our parents and grandparents. Almost half of these caregivers are also caring for at least one dependent child. The stresses on those in this "sandwich" generation are extreme, and they take their toll in mental and physical illness. We have more and more frail older Americans and fewer and fewer daughters and wives and nieces to take care of them.

Four short years ago, Senator, at another field hearing of the U.S. Aging Committee, my colleagues and I brought to your attention the "quiet crisis" that was brewing behind the closed doors of thousands of homes of older and disabled Americans. In 1986—April 21, to be exact—we brought you videotaped testimony from severely disabled patients, patients so sick that they could not get out of their sickbeds, let alone their homes. Those patients and their families told you about the devastating human impact of policies of the Federal Health Care Financing Administration which were resulting in the denial of Medicare payments for thousands of home health care claims.

At that time you pledged your help to the homebound. I am happy to report that as a result of measures which you, Senator, introduced, many more Medicare beneficiaries can receive the home health benefits to which they are entitled, and home health agencies can manage their financial affairs with more certainty.

In 1986, Medicare denied home health care to a woman in her eighties who had broken both arms and was so frail that she could not get out of bed without assistance. The Health Care Financing Administration denied her claim because they said she was not truly homebound. After all, they reasoned, once she got out of bed she had the use of her legs. The provision which you succeeded in including in the 1987 Federal Budget Reconciliation Act corrected Health Care Financing Administration, which had defined homebound to include only those who were completely bedbound.

Medicare law says that only intermittent care is covered. This is supposed to mean that a patient is not eligible to receive constant daily care. In 1986, families told of cases where they would receive 2 or 3 days of medicare-funded home care help for an elderly relative and then the family would supplement that service with 1 or 2 days per week of care, which they purchased with their own funds. Medicare would then retroactively deny payment for the 2 or 3 days of care because, with the family-paid care, the patient was no longer receiving intermittent care. Result: The family could not carry the burden, and the patient faced confinement in a nursing home at a higher cost.

Several years ago Senator Bradley made a home visit to a bedbound, severely disabled patient who was being cared for by the agency that I direct. The wife, with the assistance of the home health aide and a professional nurse, was able to keep her husband at home, but the assistance was needed for more than just a few days a week. Your action to reintroduce legislation to clarify the definition of intermittent care to include up to 7 days per week of care, depending on medical circumstances, would make a big difference in the lives of many patients and their families. This provision, lost in the repeal of the Catastrophic Coverage Act, would make the rules of the game clear and fair for all. Today the rules of the game are clearer and fairer for all, but the unfinished agenda in home health care is still long-term care.

We know this is a longer-term goal, and we need to work with you to make affordable long-term home care a reality.

On March 2, the Pepper Commission released its historic report which called for adoption of a national program of long-term care, with home care as its centerpiece. Senator, every day of the week our home health nurses see patients and families throughout New Jersey who are losing the financial and emotional struggle to meet the long-term care needs of their elderly relatives, chronically ill children, and adult disabled relatives. Studies have shown that 90 percent of all Americans say they cannot afford the cost of a long-term illness, and that 87 percent of Americans favor a Federal Government program to provide long-term care in the home.

The problem is real, and we look to you, Senator, to take the lead on addressing the long-term care dilemma, just as you tackled tax reform in 1986.

We applaud your leadership in proposing S. 2246, the Medicare Home Benefits Improvement Act of 1990, which restores several crucial benefits lost with the repeal of the Medicare Catastrophic Coverage Act. The problem with being last is that you've heard it all before, but I'm going to repeat again the four components that I would see in home care that are so important:

First, the intermittent care provision, which defines daily as 7 days per week and extends Medicare-covered home health care to a total of 38 days, I spoke to that point a few minutes ago;

Second, the provision to allow up to 80 hours of respite care services to chronically ill and/or dependent homebound beneficiaries will, as you have been told again and again, assist and encourage family caregivers. These supportive caregivers need this relief and it will bolster the family's ability to care for the chronically ill at home. The components of the Senator's legislation that require a financial threshold and a 20 percent co-payment are designed to prevent financial abuse while still providing an essential service. The agency that I direct received a small grant to provide in-home respite, and we have succeeded in keeping at home 98 percent of the patients serviced by this program;

Third, a provision to eliminate the 210-day lifetime limit on hospice care will permit patients and families to receive more of the special hospice support and care, which includes physical, social, psychological, and spiritual elements;

And finally, the provision to include coverage of certain types of in-home intravenous therapy will not only make it possible for more patients to receive services at home, surrounded by a familiar environment and support system, but it is also a perfect example of cost containment. In 1989 an analyst at an investment banking firm in Connecticut found that home infusion costs averaged just $90 patient per day. This included the necessary fluids, high-tech delivery system, and nursing support.

We urge your support during the current session of Congress, Senator, for these other important provisions:

Maintain the waiver of liability provision in the Medicare benefit. Congress has long recognized that it is not always possible to determine in advance whether or not a particular service is covered by Medicare. The waiver is a legal presumption which also serves to protect the home care and other providers when they provide services in good faith, which are later determined not to be covered by Medicare. A home health agency is presumed to be operating in good faith if it is 97.5 percent correct in its determinations. The Medicare presumption is scheduled to expire November 1, 1990, and must be renewed; and

Oppose any further cuts in the Medicare Program. The Congress has taken this position thus far in the budget process. We urge you to stand firm on this point when it comes time for the annual budget reconciliation process. Medicare has been cut enough in recent years. The 2 percent Gramm-Rudman-Hollings cutback was supposed to affect only administrative costs in Medicare. Any further cuts will directly impact on the quality of care for the beneficiaries. The excuse for not broadening the home care benefit under Medicare or Medicaid has always been that it is too good an idea. It has been suggested that people would come out of the woodwork to take advantage of the benefit if it were available, and this would have the effect of supplanting care provided by families themselves. It is very difficult to sustain this argument in the case of the 1 million individuals that have been identified who need care and have no one to take care of them. It is especially so when such people wind up in the hospital or a nursing home at many times the cost. It is also difficult to sustain this objection with respect to those individuals who are in the process of being admitted to the nursing home.

Senator Bradley and I have had a long-term relationship in addressing the provision of a broad spectrum of home care services. Senator, you not only understand the consumer preference for home care, but have taken substantial action to provide these services. Thank you for this opportunity to share our views with you, and thank you for the leadership you have provided in the U.S. Senate on home health care issues.

Senator BRADLEY. Thank you very much, Ms. Boer, for your testimony.

Let me just ask a few questions, because each of you did a really exceptional job.

I would like to ask the Commissioner the same question I asked Ms. McFadden in the earlier panel, and that's about unmet need. We know the need for long-term care is enormous, as is the need for adult day care and home care. Can you give us any sense of what that unmet need is in New Jersey?

Mr. GIBBS. It's very difficult to do in terms of having firm statistics. For the Respite Care Program, we do have a quarter of our counties with waiting lists, so we know that we have some need there. We do know our own work in placing people in nursing homes that we are able to screen out people and find alternative placements for them. We know that by looking at the population currently in nursing homes that if we had more services available in the community, we might be able to render those services.

But mostly what we know, I think, is the demographics and what is changing in America in terms of the aging of our population. While there are some unmet needs today; the unmet needs will grow in the future, and we must do something about that.

Senator BRADLEY. What do you feel is the State's role in meeting that long-term need, and how can the State and the Federal Government work together?

Mr. GIBBS. Well, I think the State and the Federal Government have to be partners, both in the Medicaid Program and other social services programs. We look to the Federal Government to be a leader and to be an active partner in those programs and to take some responsibilities on their own through the Medicare Program. But our direction here in the State ought to be that with respect to long-term care for the elderly, we provide whatever social and health services are required for them to maintain independence and live independently and with dignity, and to avoid the most costly and less preferable institutional care.

Senator **Bradley**. Mr. Lesser, let me ask you this. The premise of respite care is that it puts emphasis on the caregiver, with the thought being that if the caregiver has a little relief from the constant care, then the quality of that care—and as we have heard from any number of witnesses today, the quality of life for the family of the individual—will be much better. Do you think that's a proper emphasis?

Mr. **Lesser**. I think so. In addition to that you might indicate that if the caregiver gets a certain amount of respite, the caregiver can do it for a longer period of time. And if people are going to live longer, that's going to be an essential thing to keep out of the nursing home situation.

Senator **Bradley**. Could you give us AARP's relative to institutional care versus home care?

Mr. **Lesser**. Fundamentally, the people who are involved want to be in a home care setting. That's the desire, and it's probably the cost-effective way to do it. In addition to that the nursing homes have their own financial burdens as well, so that in the long run the home care situation is probably desirable from the viewpoint of both the beneficiary and the Federal Government and the State, as well.

Senator **Bradley**. I might have missed this in your testimony, but did you endorse the adult day care bill?

Mr. **Lesser**. Yes, we did, because it's a very important element of respite care.

Senator **Bradley**. I think that that's one of the things that people don't focus on. A hundred days of day care, paid by Medicare, essentially means in New Jersey in the first year there will be 2,000 more senior citizens who have adult day care, and by year five it will be 9,000. That means that a lot of families will be able to get some relief from the constant care that otherwise would be required.

Let me ask you, Ms. Boer—You touched on this, but it constantly hits us. Every time I make this argument in the Senate or in a conference committee or wherever that we need respite care, that we need to give some relief to people, that we need to increase home care, etc., the response is the one that you alluded to which is the "woodwork" argument, that as soon as there is a benefit everybody is going to come out of the woodwork and say that they need the respite care, when in many cases they don't need the respite care.

Now, that's the argument. We have heard today from the Ocean County office that 10 percent of the needs are being met for respite care. So what would you say? You touched on it in your statement, but do you have any other thoughts?

Ms. **Boer**. I would have to go back again to the fact that I've been an administrator for a home health agency for a long time. I have been in home health care much longer than that. In reality, look at the fact that we are still only spending 2 percent of the entire Medicare budget on home care. People have not "come out of the woodwork," so to speak.

The whole concept of the cost-effectiveness of home care is the point that has to be stressed over and over again. Until you get a little older, you don't realize how important the quality of home care is, and that is not something that you can stand on the Senate floor and say, "Hey, hey, hey, it's the best place to be." As we're older, we don't want to look for more help. We don't want to take advantage of the system. We have spent our lives paying into the system and we only want to get what is the best for us. The "woodwork" effect, I think, is a cloud that people are trying to put over it to kind of take you away from the fact that home care and keeping people at home, adult day care, and respite care for the caregivers are important benefits. When I think of one of our caregivers who managed to get out to Hawaii to see her first grandchild, just because we had a short respite program for her——

Senator BRADLEY. You endorsed the aspect of one of the bills that I introduced that would change the definition of "intermittent" so that it is very clear that this could be 7 days a week.

Ms. BOER. That has been a problem for the providers.

Senator BRADLEY. Right. Now, the question is, do you think that this would result in less institutionalization, since a lot of people are now being institutionalized for short periods of time, if they could get 7-day-a-week care in the home?

Ms. BOER. I'm sure it would. I testified before a Federal administrative law judge for a patient that we kept at home, and we provided 7 days a week, and we were denied 7 days a week coverage. As an agency it was an extremely costly thing for us, but that man, because of our 7 days, died at home. The cost of it—I don't have the figures, but the cost was so much less than if he had gone into a nursing home. I'm just as sure as I'm sitting here that this would really prevent nursing home placement.

Senator BRADLEY. Well, let me thank all three of you for your testimony, and also for your endorsement of the bills, and also for your willingness to continue to work with me as the process moves forward. We have hopes that we will be able to get an extension for the New Jersey Respite Care Pilot Project. We hope for another 2 years. We also hope that we will pass the Home Benefits Improvement Act, which has the respite care provision and increases home health benefits, IV benefits, and the hospice benefits. Then we also have as our goal to pass the adult day care bill.

Those packages, while they are not long-term care in the broad sense and as the Pepper Commission envisioned, are nonetheless actions that, as we heard from today's witnesses, can make a real difference in the lives of many, many New Jersey families and many families across the country.

I want to thank you for not only your appearance at today's hearing, but for your continued willingness to offer your counsel and advice.

I would like to thank the first panel today because it is their personal stories that carry the strongest impact on the lives even of Senators and Congressmen.

I would like to thank the second panel, who gave moving testimony that those who provide do so because they care.

I would like to thank this panel for letting us see the quality that is in the New Jersey health care governmental and interest group area, all the way from the Commissioner to one of the most well-respected interest groups.

Let me thank all of you for your willingness to testify. I think that this is a record that will help the Senate Aging Committee and that will also, frankly, help me in the Finance Committee to make the case that needs to be made to get these bills passed and into law as soon as possible.

So let me thank you for your testimony, and particularly the Commissioner for taking time for this hearing. I know, as I said at the beginning, that it was not the easiest thing to do, to come to Leisure Village from Trenton, but I know that everyone here appreciated it, and I did very much.

So with that, the Senate Special Committee on Aging is adjourned.

[Whereupon, at 1:05 p.m., the committee was adjourned, to reconvene at the call of the Chair.]

APPENDIX

Item 1

Senior Citizens United Community Services
SCUCS
a full service agency

DONNA KOVALEVICH
Executive Director
MARIE DOYLE
President

THOMAS PIERCE
Vice-President
ROBERT E. STEPHENS
Secretary
JOHN SMYTHE
Treasurer

SISTER MARY RYAN
DR. LEONARD COPLEIN
ALFRED LITWAK

April 12, 1990

Senator Bill Bradley
Senate Aging Commission
731 Hart Senate Office Building
Washington, D.C. 20510

Dear Senator Bradley:

I am writing to submit written testimony regarding the Statewide Respite Care Program. I hope you will be able to consider this testimony along with the verbal presentations at the field hearings on April 16, 1990. This program has played an essential role in improving the quality of life for many of the state's frail senior citizens and their caregivers.

We appreciate your attention to this matter.

Sincerely,

Donna Kovalevich

Donna Kovalevich
Executive Director

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enc.

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Written Testimony for the Field Hearings on Respite and Home Care Services in New Jersey

Senior Citizens United Community Services is a nonprofit social service agency whose primary goal is to improve service offered to the senior citizens of Camden County to enhance the quality of their lives, with an emphasis on those with the greatest socioeconomic need. As one of the sponsor agencies for the Statewide Respite Care Program we are acutely aware of the positive impact it has had on the target population of aged, ill or severely disabled.

This written document is being entered in addition to verbal testimony presented on April 16, 1990. We are anxious to support your efforts in securing continued funding for the New Jersey Statewide Respite Care Program (SRCP), currently funded as a federal demonstration project.

Hopefully this will convey to you the ongoing need that exists for this vital program. From its beginning in April 1988 to the present time, the Respite program has grown tremendously. With minimal initial outreach efforts, the program was able to serve 195 clients by the end of 1989. This demonstrates a critical need for this service existed prior to the inception of the SRCP. For the first quarter of 1990 we have already assisted 72 families.

Many of the families we service have been struggling on their own to provide 24 hour care for their aged, ill or severely disabled family members. This is not a group who seeks help easily. It usually takes a crisis for them to pursue outside help. SCRP is the only state or federally funded program that does not require personal care service in order to qualify. This is a critical issue for families who are often reluctant to accept this type of service (or may not qualify) but still desperately need a "break". We are easily able to provide a wide range of services including companion or medical or social day care. Many of our clients are also excluded from eligibility for other county programs due to the more stringent liquid asset limits.

For many of our families, SRCP is their first and only social service connection. This then serves as a vital link in helping to direct them to the right area and any possible entitlement program. Referrals to caregiver support groups is another means of helping families to decrease the loneliness of the situation, while at the same time offering support and education. The average age of our caregivers is 59 year old with 50% older than 70. Many of them could also benefit from some assistance. Through careful revenue allocation of the SRCP funding, we are able to serve the maximum number of clients. We can then target those people who might otherwise fall through the cracks.

Twenty-five percent of our total caseload is the Alzheimer or dimentia population. For the caregivers supporting this group, there is an acute need for respite. Not only are they faced with their loved one's physical deterioration, but also the ravages of mental decline, and for many the need for constant supervision. This places a tremendous strain on the caregiver.

As part of our yearly agency self-evaluation, all SRCP families are sent a survey regarding the services provided and satisfaction levels. Sixty-nine percent responded they were very satisfied. Seventy-six percent of the caregivers responded that respite services were helpful in preventing nursing home placement. This satisfies our primary goal of avoiding unnecessary institutionalization. In actuality the cost and amount of service provided by the SRCP is minimal when compared to providing the more costly 24-hour nursing home care. The savings for the government is significant.

The SRCP serves a critical need in our community. There is a demonstrated need for even additional home care service. Further cuts would be a great detriment to those in need. We would be more than happy to provide you with any additional information you could use.

Testimony submitted by

Donna Kovalevich

Donna Kovalevich
Executive Director