HOSPICE AND RESPITE CARE

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

ELIZABETH, NEW JERSEY

JUNE 18, 1990

Serial No. 101-23



Printed for the use of the Special Committee on Aging

U.S. GOVERNMENT PRINTING OFFICE

WASHINGTON: 1991

35-255

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HOSPICE AND RESPITE CARE

MONDAY, JUNE 18, 1990

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

The committee met, pursuant to notice, at 1:05 p.m. at the Union County Administration Building, Elizabeth Town Plaza, Elizabeth, New Jersey, Hon. Bill Bradley (acting chairman of the committee) presiding.

Present: Senator Bradley.

STATEMENT OF MR. JOSEPH SULIGA, UNION COUNTY FREEHOLDER

Mr. Suliga. We have Senator Bradley with us, the champion of health care. We realize and he realizes that over 20 percent of our population is the elderly. I consider it a real privilege and honor that he took time out of his busy schedule to hear from us this afternoon, so I would like to ask everyone to give a real warm welcome to our Senator, Bill Bradley.

OPENING STATEMENT OF SENATOR BILL BRADLEY

Senator Bradley. Thank you very much, Joseph, for the introduction. The Senate Special Committee on Aging will come to order.

Our hearing today is a very important hearing. We will be receiving testimony from a number of very knowledgeable individuals and individuals who have their own personal experiences to share with the Committee.

All of the testimony will be a part of the official Senate record. Anyone who would like to get in additional testimony has until June 25 to submit any additional written testimony, beyond that which they have already submitted.

We are aging in America. With all the wonderful advances in medicine in this country, we have not advanced far enough to escape the need to confront the final years of our lives with dignity, humanity, and the peaceful acceptance of mortality.

In New Jersey we can not only see the serious difficulties of living with aging and health problems for older and disabled citizens and their families, but we can also find some of the most innovative and effective programs in the country responding to those problems.

During my 12 years in the U.S. Senate I have often asked the Senate Aging Committee to bring our hearings to New Jersey and

learn first-hand about the importance of the long-term care needs of our elderly citizens. Two months ago I conducted a hearing in Ocean County where caregivers, providers, and advocates for the elderly came to give moving testimony on one of those programs, the New Jersey Respite Care Pilot Project. It's a small project by the standards of the Federal Government, but it has helped a great many people and has been a very special program for me personally.

At that hearing in Ocean County, I heard a young mother of three talk about the enormous value to her family of having one 6-hour period every other Saturday when a home health aide comes to give the family respite from caring for her mother, who has Alzheimer's Disease. Meredith Wagenblast was the woman, and she told me how the family cherished and planned afternoons when the family could do the things that most families take for granted, such as going bowling together or attending her son's Little League baseball game. Others have written to me to tell of the importance of respite care for them, many, many letters. One 82-year-old caregiver was permitted, because of the program, a week of care for her 103-year-old mother so that she could attend her granddaughter's wedding in California.

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 with the burdens of

caring for dependent family members.

Today, I have come to Union County to solicit additional testimony on respite care and on a very special program that New Jersey has had an important role in promoting and developing, and that is

hospice care.

When I joined the Aging Committee in 1979, about one out of every 10 Americans was over 65. Twenty years from now, nearly 1 American in 7 will be over 65. Some of our greatest medical successes have prolonged and improved the quality of life for our aging and disabled citizens. These 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.

The very success of our medical progress has made us forget at times the limits of our technological capabilities. We have been able to prolong life and improve the quality of life, but in the end, we all die. The hospice movement serves to remind us that at the end of the struggle against a terminal illness, we must help the dying patient to confront the end in comfort and with dignity. Hospice care is about helping families and victims of terminal diseases live with the reality of dying and with the pain of living in the last stages of that illness.

Too often, when people think of the aging and dying population, the image comes to mind—a very sad image—of nursing homes that are overcrowded and understaffed, or corners of hospital wards where the last gasps of life are heard behind drawn curtains. 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 not in institutions, not in

nursing homes, but by family members at home. Similarly, an increasing number of people with terminal illnesses are choosing to die in the comfort and the dignity of their homes, surrounded by

loving family members.

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 and ill citizens. If we as a Nation are to have any effective long-term strategy—and I hope we will develop the strategy soon—it will have to build on and support this valuable network of family caregivers. The terror of dying can be softened by the love and care of one's family, bolstered by a support network that helps the dying person face death. I believe that hospice care does just that.

I asked the Aging Committee to sponsor this hearing so that the Senate could learn more about how these programs work for those who depend on their help and those who are dedicated professionals charged with providing these services. Federal funding for the Respite Care Pilot Project is scheduled to expire this year, and I want to continue the funding of the program for two reasons.

want to continue the funding of the program for two reasons.

First, of course, the nearly 2,000 families that are helped every 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 that it might have. I would like to establish a similar program 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, form the nucleus of a humane approach to long-term care.

Finally, the Medicare hospice benefit has an artificial 210-day limit to benefits. One of the provisions of my Medicare Home Benefits Improvement Act of 1990 would eliminate this cap. I have come to hear testimony today on the value of hospice care to take back to the Senate in order to help me fight for this provision, and for others that will help hospices do a more effective job of helping

families care for dying family members.

I welcome all those who have come today to offer their testimony. We will be operating under some time constraints, so try to make your statement as brief as possible, and I will make my questions as clear as possible. I think that the record will benefit, the Senate will benefit, and hopefully, the resultant legislation will prove beneficial to New Jerseyans in need.

Our first statement today will be by Phil Pearlman, Director of

the Union County Division on Aging.

Mr. Pearlman, welcome to the committee. Feel free to make your statement.

STATEMENT OF MR. PHILIP PEARLMAN, DIRECTOR, UNION COUNTY DIVISION ON AGING

Mr. PEARLMAN. Thank you, Senator.

Senator Bradley, my name is Philip Pearlman. I am the Director of the Union County Division on Aging. I want to thank you for

coming to Union County today to look at the issues surrounding

hospice and respite care.

You will hear about some of these issues today from people who are receiving services. You will also hear from agencies who are providing services. Additionally, you will hear from advocates for the elderly, people who are working to resolve some of the problems affecting hospice and respite care services.

The Union County Division on Aging, as an Area Agency on Aging, is the primary agency planning for services for the elderly in the county. The highest priority in our planning for the elderly residents of the county is the needs of the frail, homebound, and terminally ill persons. The Division receives funding from Federal, State, and county sources. We distribute these funds to a number of agencies. Some provide home- and community-based care for terminally ill persons. Others provide respite services for caregivers of chronically ill elderly persons. The Division disburses funds through a coordinated care system, which we started in 1981, to the hospice, home care agencies, and adult day providers throughout the county.

From the perspective of a planning agency, a major issue is the demographic change we expect over the next 25 or 30 years. The current 100,000 county residents over the age of 60—almost 20 percent of the county population—will grow, especially as the forerunners of the baby boom generation reach senior citizen status. The migration of seniors leaving the county will not offset the elderly population growth. It will change the composition of the elderly residents. We will have a higher percentage of minority, more women, and more elderly at or near the poverty level.

During the last 9 years the Administration has attempted to reduce Older Americans Act funds and other funds serving the elderly. This direction must stop. Otherwise, we will find it difficult to meet the needs of this burgeoning population. Alternatives such as cost sharing will not expand services for the poor or near poor. More restrictive eligibility requirements will only leave more

needy people out of the system.

We need the continued concern and actions of you, Senator Bradley, and the other Members of Congress. The time has come to address the current unmet needs of the elderly population. We must also prepare for the needs of a growing and graying population in the future.

Thank you for your attention and continuing interest in the

issues and problems affecting the elderly.

Senator Bradley. Mr. Pearlman, thank you very much for your testimony. I can appreciate, in your role as the Director of the Union County Division on Aging, how you have been affected by cutbacks at the Federal level or the State level in programs that help the elderly.

Do you have any particular area that you feel has been hardest hit?

Mr. Pearlman. I think all of the services that we refer to as "in home" or "community-based" services are among those which are hardest hit. The demand keeps growing, and as the funds don't grow to meet those needs, the pinch is getting felt.

Senator Bradley. So the Medicare Home Benefits Improvement Act that I've introduced this year, that would almost double the days of home health care that is available, is something that would be beneficial to the senior citizens of Union County?

Mr. Pearlman. Absolutely.

Senator Bradley. Thank you very much, Mr. Pearlman, for your testimony and your willingness to come today.

Mr. PEARLMAN. Thank you, Senator.

Senator Bradley. Our first panel consists of individuals who will give profiles of beneficiaries, those who have benefited, and also caregivers. As I mention your name, would you please come up and take your seat where you see your name?

We have Thelma May Smith, who was a caregiver for her father,

Randall Smith, who died of prostate cancer.

We have Owen Morrison, who was a husband and caregiver of his wife, Doris, who succumbed to a 13-year fight with breast cancer.

We have Joe Moore, husband and caregiver for wife Joan, who

died at home of Lou Gehrig's Disease.

Then Dorothy Jensen, daughter and caregiver for mother, Dora Gabriel.

Raphael Grimes, son-in-law and caregiver of Josephine Shekus.

Thelma Perkins, caregiver for mother Nannie Day.

And Bernadette Dwyer, caregiver for father-in-law, Thomas

Dwyer.

So I would like to welcome all of you to the committee today. The committee is now prepared to receive your statements. Let us begin in the order that you were called. Again, try to make your statements within a reasonable length of time because we have many people we want to hear from today, and we want to give everyone the opportunity to share their experiences with the committee.

Ms. Smith, welcome to the committee.

If anyone is cool, or if anyone is warm, let me know—

Ms. Smith. How about just nervous?

Senator Bradley. Well you should feel reassured that everyone here wants to hear your story. The purpose of these hearings is to be as informal as you can, even though you have a stenographer.

STATEMENT OF MS. THELMA MAY SMITH, CAREGIVER FOR FATHER. RANDALL SMITH

Ms. Smith. My name, again, is Thelma Smith. I was the caregiver for my father, Randall Smith, who passed away this past Feb-

ruary of this year.

As a little background, I had a twin sister who died at the age of 7, died at St. Elizabeth's Hospital in Elizabeth, NJ. from that time on my father tried to stay away from that hospital. Over the years he had 3 doctors, finding out later that they only practiced at St. Elizabeth hospital. The more he tried to avoid this hospital the more he was forced back. My mother passed away in December 1987, and she was diagnosed with acute leukemia, and was diagnosed in St. Elizabeth's Hospital. I say that so that you will understand why my father had very negative feelings toward St. Elizabeth's Elizabeth's Hospital.

beth's Hospital when my father was diagnosed with his cancer the Doctor and I sat down and discussed it, we knew that we did not want to put him in the hospital. I was strongly in favor of that, and we looked for and sought help through Center for Hope in Roselle.

They were like a partner for me, without a doubt. They knew where I was coming from. They knew what I was searching for. They could anticipate my needs, ones I did not know. I would have.

My father would have been 86 this past May. I worked two jobs, so as a caregiver I was really put to the ultimate in giving him quality care with friendly, understanding people, and that's what I wanted for him. I wanted him to be home, surrounded by people who loved him.

From the point Center for Hope entered my house, it was just a totally different environment. My feelings today, as far as my father's death goes, are that I am very comfortable and very proud of his death. That is totally different than my mother's situation, and I am still dealing with my mother's death, even though it's 2½

years later.

I should backtrack and say that with Center For Hope I had to deal with just one phone number, and that meant so much to me. Anytime I needed anything it was just, "Call Center for Hope. They will take care of this." If it was a prescription, or when we finally had to get the medical bed for him; if I was concerned with his reaction to medication or how he was feeling or how he looked, I just picked up the phone and dialed one number and they immediately responded to me. I wrote Center for Hope a thank-you letter and I said to them that I was just so thankful, even with the nurse who came in—I think sometimes she smiled more so for me than she smiled for my father. I felt that support, and that gave me the added strength that I needed.

Without a doubt, withou Center for Hope this could not have

been as positive an experience as it was for me.

I thank you.

Senator Bradley. Thank you very much, Ms. Smith.

Now. Owen Morrison.

STATEMENT OF MR. OWEN MORRISON, HUSBAND AND CAREGIVER OF WIFE, DORIS

Mr. Morrison. Thank you, Senator.

My wife, Doris, battled cancer for 13½ years. The last 2½ years

of her life was spent with Center for Hope Hospice in Roselle.

Without the Center for Hope I don't think that the family—which at that time was just myself; my son was away in college—I don't think I could have survived the ordeal, because without the Center providing all the services that they did, nursing care, health aides, volunteers who came in every night to help me turn my wife because she couldn't move, and all the medications and the instructions that they gave me to give injections and the pain control. Like Thelma over there said, there was just one number you had to call, and everybody would respond in short order. You could call 11 o'clock in the morning, 2 a.m. in the night, and within a short period of time there were nurses there to help you.

As I say, without the Center there to give you moral support. since I was the only one available as a caregiver, your daily functions still have to go on-they would send people up to sit while I could do the banking, the food shopping, or any other errands. Even going up to the college to Parents' Day, they provided services all day long, which amounted to about 10 hours.

Without that, I don't think I would have survived the 21/2 years. They provided everything, moral support, all the medical, the hospital bed. There was nothing that I requested that I really didn't

Senator Bradley. You were associated with the hospice caregiver

for how long?

Mr. Morrison. For 21/2 years. As I say, without them, you couldn't survive, not for a long period of time. I know that when she was told that she was going to be terminal you expect a 6month period, but as I say, she survived 2½ years. That's a long time to be locked up for 24 hours a day, which you virtually are, because you need that assistance, and they provided it. Senator Bradley. Thank you very much, Mr. Morrison.

Mr. Morrison. Thank you, Senator.

Senator Bradley, Joe Moore,

STATEMENT OF MR. JOE MOORE, HUSBAND AND CAREGIVER FOR WIFE, JOAN

Mr. Moore. Yes, Senator. Thank you for the opportunity to

share a little bit about my experience.

In 1986 my wife was diagnosed with ALS, Lou Gehrig's Disease. Basically, we had a second opinion in New York and came back totally devastated because we were told at that point that there was no point for her and, basically, "Go home and die." When you've been with somebody since you were 18, for 30 years, and she was much healthier than I have ever been, I was also devastated.

Thank God for the Center for Hope. I knew of them. I had heard about them in the community and the great things that they have done. I was also told that when it was time—and that time, I was under the impression, was 6 months—that we would have to go to a hospice earlier than that, because I was trying to maintain a

business, my livelihood, and my wife needed continuous care.

I guess if I was to say, more than anything else, what hospice did for my whole family, my wife and me and the four children that I have, it was especially for my wife. They allowed her to die with dignity. That's more important than anything else. The holistic approach that hospice has, the physical, the mental and the spiritual, not only helped me personally, because I had reached a point where I thought that I was going to die before she did. I was totally exhausted. I had taken her in to the hospital because the disease was getting to the point of respiratory problems, and I had left her and was gone for a few hours. I was under the impression that she was being taken care of. I walked into that hospital room, and she hadn't been taken care of. Of course, with Lou Gehrig's Disease, while the body dies, the mind doesn't. She was able to just look at me, in her tears and her crying, and ask me to take her home. She just wasn't being taken care of, because at this stage of her disease

she couldn't move her hands or her fingers, or she couldn't move herself.

But hospice came in and they took care of her, of all areas of her needs.

One of the things that I love to share about her death is that she was a fantastic gal. We had converted the dining room into a hospital room, basically, with the bed, with the Heuer lift, and I had taken her out of the Heuer lift to put her into the wheelchair and went in to prepare breakfast for her. All of a sudden I heard a cry. I went in and I sat on the bed and I took her fingers and her hands—that was all that was able to move at this stage in her disease—and we cried and talked about her dying, and all of a sudden she stopped and said, "Okay, that's it." I said, "What do you mean?" She said, "I'm only allowing myself 10 minutes a day to feel sorry for myself. Let's get on with life." That is how big she was over the last 2 years.

I don't know what I can say about hospice, other than, thank God for them, because if it wasn't for them I don't know what would have happened to us, the whole family. I'm not just talking about my wife or myself, I'm talking about the whole family.

Thank you.

Senator Bradley. Thank you very much, Mr. Moore, for your testimony and your story.

You were with hospice for how long?

Mr. Moore. About 7 months. Senator Bradley. Seven months.

Mr. Moore. My wife was diagnosed for 14 months.

Senator Bradley. Our next witness is Dorothy Jensen.

STATEMENT OF MS. DOROTHY JENSEN, DAUGHTER AND CAREGIVER FOR MOTHER, DORA GABRIEL

Ms. Jensen. Good afternoon, and thank you for permitting me to come.

I have an 89-year-old mother who lives with me. She has been living with me for 2 years. She has had many strokes. She has a bad heart condition that she sees doctors for, and she's very arthritic. Arthritis is completely through her body. She needs a metal walker in order to walk. She does have mini-strokes from time to time. She doesn't fall every day. She had one last night, and that's the first since February or March. But there is no way she can live alone because every time she has a mini-stroke she loses a part of her memory.

For the first year, I tried to manage her. She would always fight me. She didn't want to take a shower. She would say she would, and didn't wash. If I tried to help her, she resented it. It was really

a bad situation.

Through the senior organization I belong to I heard of the Senior Office on Aging. I called them, and they made arrangements for respite care, which I get three times a week for 2 hours, which is a Godsend, a blessing to me. I cannot say enough about this woman who comes in for these 2 hours, gets her into the shower. We have a chair that she puts in the shower so that my mother can sit. She washes my mother down, gets nice, clean clothes on her, does her

hair once a week, gives her a lunch, and just a little companionship for her. It also permits me to be able to go out for the short while that she is there.

My husband is 71 and not in good health. I am 67, so we are all up there, and we all have our problems, so it makes it very difficult. Now, when my mother fell last night, had this new stroke, if I were alone I would not have been able to get her up. She was dead weight. I really needed my husband at that point, and thank Heaven for him, because what family I have lives too far away to be of any help to me at all.

The only alternative, as my mother progressed to this point—as I said, with each mini-stroke that she has, she loses part of her memory, too—it would really be necessary for us to put her away because we would not be able to manage her, because she just does fight us continually when we want to help her do something for her.

If I had one thing that I would wish for, it would be a few more places that would take people like my mother in order for us to be able to go away. Most nursing homes will not take respite care, and if they do take respite care, sometimes they will say, "Well, you have to have it for a month," or they don't want it to go beyond a week. Some of them absolutely refuse to take a respite patient. The ones that are affiliated with the Senior Office on Aging are so few, and the list is so long, that it is very, very difficult. That is something which I think we would all appreciate, if we have people such as my mother, who is not terminally ill—she's not Alzheimer's; you can hold a conversation with her, and you might not want to believe everything she's telling you because it might not be so, but basically I don't think she would really belong in a nursing home. She would have to go there simply because of the circumstances in our lives. Without this help, we would be forced to do that.

I thank you.

Senator Bradley. Thank you. So, you utilized respite providers, three times a week, 2 hours a day?

Ms. JENSEN. Right.

Senator Bradley. And it is in-home service?

Ms. Jensen. Yes. She comes to the house. She is wonderful, she really is.

Senator Bradley. Thank you.

Our next witness is Raphael Grimes.

STATEMENT OF MR. RAPHAEL GRIMES, SON-IN-LAW AND CAREGIVER OF JOSEPHINE SHEKUS

Mr. Grimes. Right here.

The whole thing is, it's my mother-in-law and father-in-law. My father-in-law had cancer about 2 years ago. We had the hospice people, and we're very thankful for it because, as everyone has stated, we couldn't help him. He was in bed. They got the cot and they got everything for him. He had a few bad moments in the middle of the night, 2 or 3 o'clock in the morning, and all it took was one phone call and they were there within 10 minutes. They were very fast. They came every day to change him and bathe him

and do all the things they had to do. They wouldn't let me in the room, so I don't know what they did. They closed the door. But when they came out, he always had a smile on his face. He was

happy, whatever they did.

He was like that for about a year. We had a big party one day, and he died the next day and he was in his glory. There was so much to be said about that, that we went up to see-I can't think of his name now, the Father that ran it, Father Hudson-I live in Cranford, and we went up to Roselle and we talked to him. This man, I don't know where he gets it from, but he's a saint, I'll tell you that. He helped-

Senator Bradley. Maybe that's a clue.

Mr. Grimes. He came to the house. We talked again, a couple of times. I was working at that time. My mother-in-law, who is Mrs. Shekus, Josephine, she got very bad after he passed away. She sort of forgot things and everything else. We had her for about 2 years. I had to retire to take care of her, because my wife was working and she couldn't get off, and I was ready to retire. So I retired, and I've been taking care of her for 2 years. Last year it got so bad that I had a double bypass. I couldn't stand it much any more. The

doctor said it was just stress that did the whole thing.

When we heard of this respite care—my sister-in-law heard about it while I was in the hospital, and she contacted the people at the Division On Aging of Union County. They have been taking her every day from 8:00 o'clock in the morning until 4:45 in the afternoon. We call it "school" because otherwise she wouldn't go. If we said that she was going to something like that, she wouldn't go. But she goes to "school." She gets up early, she gets up at 6:30 or 7 o'clock to make the 8 o'clock bus. She is very happy, and she comes back with all the beads that she's made, all the little things that she's made, and she comes back with a happy mind.

This is what has helped as far as we are concerned. I had to recuperate, and I just couldn't do it. If she fell, which she did a few times, I had to call a neighbor in, have her lay there until I came

back, because I couldn't pick anything up.

As I said, right now she's in a very happy state of mind, and my wife and myself are the same way, of course, because we can sort of live a little life of our own. When we go on vacation, we have to get my sister-in-laws to come and stay with us or take her for that time, because she can't be alone. She just follows you around the room, won't look at television. She's on your tail at all times.

Senator Bradley. So you have a respite care person, one person

who comes in?

Mr. Grimes. No, no one comes in. She goes to "school." They pick

her up in the morning.

Senator Bradley. I see. The purpose of this is to elicit your personal stories and to see where the help has come from and how each of you feel about that help.

Mr. GRIMES. Like I said in my letter, it's like the light at the end of the tunnel that I've seen at the end. We've been very happy

since that time. We hope it really keeps going.

Senator Bradley. Right. Thank you very much, Mr. Grimes. Our next panelist is Thelma Perkins, who is a caregiver for Nannie Daye.

STATEMENT OF MS. THELMA PERKINS, CAREGIVER FOR MOTHER, NANNIE DAYE

Ms. Perkins. I'm here on behalf of Nannie Daye, my mother. She is 85 years old. She is a very sweet person, but sometimes she really doesn't want you to do anything with her. But the nurse is such a blessing. I don't know what I'd do without her.

She comes twice a week for 2 hours, sometimes 3 hours, and she bathes my mother and she feeds her, cooks her breakfast, combs her hair, and it's just a blessing. She takes her for a walk, and it's

a blessing to have someone to help you with her.

I also have my father. They have been married 67 years, which is also a blessing. He can handle himself pretty good. My mother is very cute, because sometimes you'll ask her if she's married, and she'll say "no."

I appreciate what you've done for her. It's really a help to me, and it's a pleasure for me to come out and say that. Thanks a lot. I wanted to let you know that I do took a proposite it.

wanted to let you know that I do truly appreciate it.

Senator Bradley. So you get respite care about two times a week?

Ms. Perkins. Yes.

Senator Bradley. For how long each time?

Ms. Perkins. From 10:00 to 1:00.

Senator Bradley. And that allows you to do——

Ms. Perkins. It allows me to do what I have to do. It's just a blessing to make sure she's taken care of.

Senator Bradley. Right. Well, thank you very much.

Ms. Perkins. Thank you.

Senator Bradley. Our last witness on this panel is Bernadette Dwyer, who is a caregiver for her father-in-law, Thomas Dwyer.

STATEMENT OF MS. BERNADETTE DWYER, CAREGIVER FOR FATHER-IN-LAW. THOMAS DWYER

Ms. Dwyer. Thank you, Senator Bradley. I am Bernadette Dwyer, and I am here to talk about the Respite Care Program.

I take care of my mother, who is 78, and my father-in-law, who is 83. He's the fellow who is under respite care. He has had many strokes and has been disabled since he was 58. He retired on disability from Exxon and has had many things wrong with him because of the black lung disease. He falls a lot, but he is able somehow to manage his own place, as is my mother. And for both of them—because I have four children still at home—we have a lady coming for my mother, and she has to pay for that on her own, but my father was not able to, so we applied for the Respite Care Program.

A woman comes in 5 days a week, 2 hours a day. She is just such a good help. She bathes him, makes sure he takes his medicine, does his wash, and the best part about it is that before she leaves she will call me and tell me if Pop is all right, and that gives me a real lift for that day.

Occasionally she has had to call me and tell me just the opposite, that he's not good, that he's falling, that he's not feeling well, and please come over right away. If she wasn't there, I might not know

that. I wouldn't know it, because I get over there every afternoon,

and she comes in the morning.

Parenthetically, I didn't know if Father Hudson's program was going to be here today. When I lived in Clark for 20 years, we had neighbors next door who had no children, no family at all, and very few friends. They stuck to each other very much. The lady got sick, and she had no one. We didn't know what to do. I was fairly close to them, living next door, so I called the Center for Hope. A lady was out the very next day, and she came almost every day until the woman died, 3 months later.

Thank you, Father.

And thank you, Senator.

[The prepared statement of Ms. Dwyer follows:]

31 Colore. Would, New Providence, n.g. 07974 June 9, 1990

The Donnable William Bradley Yested States Senator Washington, D.C.

Re: Regpite Cue Progrem

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Senator Bradley. Thank you very much, Ms. Dwyer, for your testimony.

Let me ask the panel generally, particularly those who have been recipients of hospice care, how did hospice care allow you or your family to come to terms with the inevitable death of a family member? What specifically did hospice do to allow you to confront

and accept that fact?

Mr. Morrison. When my wife was told that she would be declared terminal, we met with Peggy Coloney and she explained everything to both my wife and myself and what the circumstances are, living at home and dying at home, very peaceful, the care, and so forth. I think that without that—we also talked with Father Hudson—but without that, if we were just left alone, I think you would have been struggling yourself on doing things right or not, and so forth. But they came out and explained everything to us, the circumstances.

Senator Bradley. So it was information, basically, that reassured you that even though there were a limited number of months left, you were talking with people who had been there before and who understood how to assure the maximum comfort for your loved one?

Mr. Morrison. That's right, yes.

Ms. SMITH. I felt more comfortable talking with the people from Center for Hope. They talked more down to my level, and I didn't feel as though it was a stupid or dumb question that I had for them.

I found out more about his condition from them than I did from the doctor. They gave me every stage that was to come. They told me in advance what was going to happen. And every time the nurse came out, she always called me at my job and said, "Listen, I just saw your father, and this is where we stand with this, you can look out for that," but it was just far better communication and a far better relationship than I knew I was not going to get from the hospital. Not to take anything away from the hospital, but they are family to me.

Senator Bradley. It's a different function.

Ms. Smith. Yes, exactly.

Mr. Moore. I can also echo that same thing. What they actually did for me was to walk me through the whole process of the death. I had never been exposed to anything like this before, and very few people know anything about Lou Gehrig's Disease. When something difficult was changing, they were able to explain to me the process of what was going to happen. At the end, I was prepared. I had also been going to JFK Hospital. On Monday nights they had a support group for ALS caregivers, and I was being filled with so many negatives that it was just becoming overwhelming. Thank God for the people at hospice who are sensitive and compassionate in realizing that this was a process that I was also going through.

Senator Bradley. So they not only gave you information, but they directed you to where you could also get support from people

who were situated similarly?

Mr. Moore. That's right. And of course, as you can well appreci-

ate, the bills, the oxygen, all the--

Senator Bradley. Now, what would any of the three of you have done if your loved one was receiving hospice and the magic day of

210 arrived, and you would have been cut off? I imagine that all three of you could not have dealt with that.

Mr. MOORE. No way. It would have been overwhelming for me,

because it was a continuous process-

Senator Bradley. So it would be like somebody taking you right to the point where all of the preparation is either going to give you help or not give you help, and then leave you?

Mr. Moore. Right.

Senator Bradley. Abandon you?

Mr. Moore. Abandonment. It would have been total abandonment, that's right.

Senator Bradley. And we have defeated the whole purpose of

the hospice to begin with.

Mr. Moore. I concur with that 100 percent.

Senator Bradley. Well, let me ask the respite care recipients, as specifically as you can, how did the fact that respite care was going to be provided, and was provided to your loved one, affect the family?

Ms. DWYER. We wouldn't have been able to afford home health care for my father-in-law, so we would have had to bring him in

with us. This way he is able to stay in his own apartment.

Senator Bradley. So it freed you?

Ms. Dwyer. Yes.

Senator Bradley. You cared for him—you said they came how often?

Ms. Dwyer. They come 5 days a week.

Senator Bradley. Right. So it frees you to actually—

Ms. DWYER. To have the mornings at my own home with my family and not have to go out. I make his meals and bring them over every afternoon.

Senator Bradley. So if you didn't have this routine, someone

would have to be with him in the morning?

Ms. Dwyer. Yes, but that's not available, Senator, so he would have to come and live with us.

Senator Bradley. And then you would have to give 24-hour care?

Ms. Dwyer. Yes. I don't know how we would manage that.

Senator Bradley. Or someone would.

The point is, respite gives people a break?

Ms. DWYER. That's what it is, exactly.

Senator Bradley. I think that what members of the Senate don't always understand is the amount of stress that develops on a family as a whole when there is the need to provide care constantly for a loved one, and the feeling you have when that's not provided.

Ms. Jensen. That's very true. With the care that we have for my mother, it eases the burden. Now, my mother is able to feed her-

self—-

Senator Bradley. So what do you do with that time?

Ms. Jensen. What do I do with the time when they are there? Well, oftentimes I will run and do locally little chores in the area, because the caregiver comes over the lunch hour. So she feeds my mother lunch, along with taking care of her personally.

But what I'm saying is that the importance of what she does for my mother, that is the most stressful thing for me because my mother thinks she's clean and doesn't have to do these things, making it an impossible situation for me. With respite, I feel that somehow I can cope.

Senator Bradley. So in other words, when the respite care provider arrives and provides some care, you then go and do your errands or whatever?

Ms. JENSEN. Right.

Senator Bradley. And the point is, you know that she is being taken care of. You come back to her refreshed?

Ms. Jensen. Absolutely. Absolutely. I don't ever have to worry that my mother is going to run away—so it means everything to me. It really does.

Senator Bradley. Okay.

Does anyone else have any comment?

Ms. Perkins. I would just go along with what she said. It's a relief to know that someone is there. My mother used to try to get away, leave the house, but after I got the nurse coming in and she talked to her, she sort of acts like she looks for her. It's a blessing to have her. She kind of looks up to her, and she looks like she really enjoys it, they enjoy each other. It's just a blessing to know that they can get along so well together.

Senator Bradley. Well, let me thank all of you for offering your stories which are, from my perspective, the best way to try to understand the effect of policy and laws and regulations on people, to hear about the lives that are affected by the fact that these services are available. The purpose of this hearing is to have a record so that we can determine the extent to which things should be changed or expanded, and I think that your testimony today on respite and hospice, from a very personal perspective, is enormously helpful to me, and I think it is also for the whole Senate. So I thank you very much for sharing your stories with us today. Thank you.

Our next panel consists of providers of hospice and respite care. We have Margaret Coloney, who is the President, Center for Hope Hospice, who will also bring Peg Ross, a volunteer hospice home health aide, to testify; Sarah Miller, Jewish Family Service, who will bring Mrs. Jennings, a home health aide who will also testify; and then Victoria Hasser, who is the Director of WISE Social Day Care Center.

Let me welcome you to the committee. I look forward to your testimony. If you could, as we have in the previous panels, as you have witnessed, try to be brief and then we will have a little time for questions and discussion.

Let's begin with Margaret Coloney and Peg Ross. You are from the Center for Hope. We have just heard a panel where it seems that every other word was "Center for Hope," so we are very pleased that you could be here today to share your own perspective on the legislation that is pending. STATEMENT OF MS. MARGARET COLONEY, PRESIDENT, CENTER FOR HOPE HOSPICE; ACCOMPANIED BY MS. PEG ROSS, VOLUN-TEER HOSPICE HOME HEALTH AIDE

Ms. Coloney. Thank you, Senator. I am known as Peggy Coloney. I don't usually go by Margaret.

Senator BRADLEY. Oh, fine.

Ms. COLONEY. That's fine, but I'm just saying that sometimes when someone says "Margaret," I have to look twice.
Senator Bradley. Let the record show that the Chairman re-

ferred to Ms. Coloney as Peggy.

Ms. Coloney. Thank you.

I am the President of the Center for Hope. I really feel that anything that I had to say could certainly be eradicated, because I had

such wonderful witnesses prior to coming here today.

I wanted to speak and explain to the Senator our feelings about the need for in-home respite, basically because for the Center for Hope, we have an advantage. We are a free-standing hospice. Many hospices don't have the advantages that we do. I think that when people speak for the Center for Hope, it's really hospice that they're speaking for. It's the philosophy that hospice brings to the health care field.

But for the patients that want to remain in their own homes, for the couple that has lived their lives together and who do not have a primary care person, who do not have a support system or anyone that can give that added support and that extra care that is needed at this time, respite service is very, very important in the

home.

We have had testimony from three of the patient survivors, and I think that speaks for itself. I think that it shows that when a person dies, only one person's life is over, and that life goes on for the rest of the family, for the family member that was the caregiver and for the other family members that are doing the things involved with living. It's almost expected of this person to be able to go on. When we have all the trauma and all the stress and the increased anxiety that a terminal illness brings into a family situation, it's very difficult, as symptoms change and as new services have to be expanded, that we should feel that it would be our obligation as caregivers to be able to provide this service to these families who are very willing and able to accept this responsibility. It's the one last wish, many times, that a dying person has, to be able to remain at home, to be with the family, to be surrounded by the comfort and love and security of the home and not to have to be isolated from the family and, so to speak, have death occur earlier in their life by that type of a separation, to be able to be in that home and to see what is going on and to know that they're going to stand together and support one another.

That is what all this comfort to a dying patient is about, to see that they can get along, to see that this person-whatever their role was in the family-to see that somehow their investment into this family has allowed the support of the family enough that they

are going to get along and continue as a family.

At the Center for Hope we have many, many advantages. We have, at the present time, received a Certificate of Need to have a residential inpatient facility. In July, we will open the first inpatient facility in the State of New Jersey. This will be for patients who do not have family members, who do not have anyone to support them, who cannot afford to hire a caregiver or who do not have insurance or opportunities for anyone. Maybe they don't even have a home, and maybe if they do have a home, they don't have a safe and secure environment. So for those people, we are going to be inviting them to come into our home from wherever they are to spend their final days. That's going to be right here in Elizabeth, and we feel real excited about that.

So I think that's pretty much how I feel about it. [The prepared statement of Ms. Coloney follows:]



E. FOURTH AVENUE SELLE, NEW JERSEY 07203 LEPHONE 241-1132 Margaret Coloney, R.N.

Pr. Charles Hudson Vice President

Robert L. Wegryn, M.D. Medical Director

Virginia Quintong, M.D.

HOSPICE ISSUES BEFORE THE 101st CONGRESS

Home Respite Care

Legislation addressing in-home respite care is favored to maintain patients at home/families together.

The Hospice Movement is eager to be attentive to the terminally ill, most especially in their homes, whenever possible. This, of course, is very taxing to the most loving of family members because of the intensity and stress emotionally and physically. In the heart of the situation, it is clearly visable the difference respite services makes whenever it is a possibility.

It seems most insensitive in those final days for family members to be separated, after they weathered the storm of the course of a disease.

Physical burnout or emotional fatigue can most certainly be prevented by providing respite in home services.

Aside from the opportunity for a family to remain such until the end, the anticipatory grief experienced by caregivers in the family, serves as a beginning for dealing with the grieving process.

We have witnessed over the years the survivors of those who have died. In situations where caregivers remained with the person throughout the journey of their illness supporting and offering every assistance, a healing takes place for all. In similar situations where the course of the illness extended beyond the energy of the caregiver and placement outside the home was necessary, the grieving process held many regrets.

Most often the caregiver feels they abandoned their loved one when they were in need. They feel guilty for not being able to grant that last wish "to allow them the opportunity to remain at home."

Sometimes it's just a matter of days, but it haunts the survivors for life.

The cost of placing a H.H.A. in home for respite is a fraction of placing a terminally ill person in a facility. While cost is most certainly an issue for arguing the point, more important an issue is the indignity to man.

Hospice caregivers want to provide this service. A tremendous investment is made by all in each unique scenerio. Whether conditions are rich or poor, the comfort of one's home, whatever that may be, offers a sense of security and control that should be available to all, if they wish.

By allowing respite at home, the caregivers would have the needed support. With the guidance and understanding of the Hospice team alleviating and reducing fears and anxieties, families would remain together until the end.

Residential Care for the terminally 111.

Addressing respite/residential care for the terminally ill, Hospice should be an option for all. Misfortune of not having family, home or caregiver, should not prevent anyone from being allowed to die in an environment that serves as a safe and caring sanctuary. Simply to invite, so to speak, one desiring palliative care to spend their final days in a home-like environment.

Much of the pain experienced by these patients, is of being alone, unsupported, abandoned and uncared for.

They are not sick enough to remain in a hospital nor well enough to remain alone. They are not seeking pity, but respect and human compassion.

Offering a refuge to those in need and Hospice care to those who choose this philosophy is our responsibility.

The Center For Hope Hospice has obtained a Certificate of Need for a residential facility for these terminally ill patients. This will be the first in the state of New Jersey.

3. Reinstatement of Fourth Benefit Period.

The reinstatement of Fourth Benefit period is supported by Hospice as an opportunity for continuity of care.

Making changes at the end stage in the very final days when emotional and physical conditions are exhausted is most traumatic.

Financial costs are increased no matter what the alternative choice is. Studies prove the cost savings of care at home.

Admission into the Hospice service might be discouraged if a person feels he might run out of benefits at the very end. At times, a patient avoids a necessary timely election to hospice.

This increases cost which occur in stablizing and controlling late admissions. Many times, caregivers are burned out and exhausted and victims of increased anxiety. If hospice receives these families in an earlier time span, education to the primary care person can avoid placement of additional services.

4. Intravenous Therapy at Home.

Hospice embraces symptom management and at times hydration, I.V. Therapy, is an option for patients to maintain a level of comfort at home.

This is not a prohibitive cost.

I.V. Therapy in it's simplest form could be refused by the patient and alternative methods would be employed. The rights of the patient would not be violated.

Pain Management: Infrequently, exhausting simpler, non-invasive pain control, intravenous infusion is necessary. This is the decision of the Medical Director and conforms with the philosophy for symptom management.

I.V. antibiotics: In rare occasions, this is the medically prescribed, necessary treatment for specific infections. A patient should not be denied this treatment which can be efficiently, safely managed at home.

Transferring and causing burdens to a patient/family is not cost saving nor humanly respectful. If changes must happen, perhaps a time has come for the systems to absorb some of the change.

We hope that we learn not only how to treat the pain and distress of our patients, but also how to understand them and never let them down.

Senator Bradley. Thank you very much.

How will that be financed?

Ms. Coloney. The same way that the Center for Hope has financed everything. We are Medicare-certified, Senator, so for patients that have Medicare, as an opportunity, we will bill Medicare Services. For patients who have commercial insurance and have a hospice provider, we bill that.

Senator Bradley. So you are basically just moving to another lo-

cation?

Ms. Coloney. Exactly.

Senator Bradley. You're adding a location.

Ms. Coloney. We are offering our home.

Senator Bradley. Great.

Peg Ross, would you like to make a statement?

Ms. Ross. Yes, I would, thank you.

I've been with the Center since it began. I work on a volunteer

basis. I firmly reinforce everything that Peggy has said.

If you ask me if I think I make a difference in the home, yes, I do, and I say that very, very candidly. About 30-some years ago I was a primary caregiver in my own home. My mother was diagnosed as terminally ill, so I've been on both sides. I can see the need for the support for the family and for the patient.

I have a feeling that you cannot go into a patient's home almost daily and bathe them and not develop some sort of a relationship

with them.

I find that this has been happening to me since I've been with the Center. They're more than patients to me; they're my friends. We talk. We have fun together, if that arises. We cry together when that arises. They know I'm there for them, and their family knows I'm there for them.

I had a case where I was with an elderly gentleman 3 days a week. He lived with his daughter. She was a single parent and had to work. I got to know Elmer very, very well. He said to me one day, "You had better call my daughter home." I said, "Why do you

want her to come home?" "Because I'm dying today."

Knowing this gentleman and knowing his thoughts and his feelings over the months, I went to the telephone and I called the daughter—she worked nearby—and I suggested that she come home for lunch because Dad was down. She was not in the house 10 minutes when she sat down right next to him on his bed, they held hands, and I would say that he died about 5 minutes later. I walked out of that house 10 feet tall because I made the difference that day.

Senator Bradley. That's an amazing story. I imagine you have

many. Thank you for sharing one of them with us.

Ms. Ross. Thank you for allowing me.

Senator Bradley. Sarah Miller.

STATEMENT OF MS. SARAH MILLER, JEWISH FAMILY SERVICE, ACCOMPANIED BY MRS. WILLIE JENNINGS

Ms. MILLER. Good afternoon, Senator Bradley. I also appreciate the opportunity to talk with you today.

I am a social worker in charge of elderly services for Jewish Family Service of Central New Jersey. We serve the aged by helping older adults and their families to plan for supportive care, to manage community services and resources. We offer support groups and supportive counseling, and we have a homemaker/respite care program. We are a provider agency for the State Respite Care Program, and we are very pleased to be working with the State of New Jersey and the Union County Division on Aging to help caregivers who are desperately trying to keep their loved ones at home.

Study after study documents that older people provide the majority of care in this country, as you have so well said. The family caregiver often puts in a 36-hour day and gets very strained and worn by the caregiving they give their loved ones. In order to have the strength and the courage to go on, caregivers must have respite in order to do family business, in order to shop, in order to go to their own doctor appointments—because they often begin to fail, as one of your caregivers told you—and sometimes, just in order to have a break.

Our service provides homemakers who go into the home, stay with the person, do some light housekeeping and laundering, and

help with meals, so that the caregiver can get a break.

When the caregivers know that there's somebody like this who is coming on a regular basis each week, they feel less isolated, more supported by their community and more able to cope. They tell us this quite often. Our homemakers provide a few hours of care each week, as you have seen. The families choose how they want their care delivered, as far as possible.

During the past year we have helped 14 families by providing these homemaker services to them so that the caregiver could get out. While this might not seem like very much service, our experience is that families are really helped by this respite, that the service really does make a difference in their struggle to keep their

loved ones at home.

The cost of the service is small compared with having to maintain an old person in a nursing home. If respite care helps a family keep their loved one at home even a few months longer, then it has

been a successful endeavor.

Jewish Family Service wants to go on record as being strongly in support of your State Respite Care Program, and we hope you will find a way to get the Senate to fund this program and other programs which support family caregivers generously in the future.

Senator Bradley. Thank you very much, Ms. Miller.

Mrs. Jennings, would you like to share anything with the committee?

Mrs. Jennings. Yes, I would like to share something.

Good afternoon. My name is Willie Jennings, and I am here today on behalf of the Jewish Family Service, of which I am a member, and have been since 1976. From the first day the homemaker program began I was there with them, and I'm still there.

For some time I have been caring for some Alzheimer's patients. Let me share a little bit of my experiences with one of my clients. For example, I have a man I am helping. He is the caregiver,

and I am a caregiver reliever. He takes care of his wife. She's an

Alzheimer's patient. He has been caring for her for a long time. But I know that I have been a help to him. The most important thing to him is to be able to get a little relief. He goes out, because this is a 24-hour job. He doesn't want me to do any work. He just wants me to take care of his wife and see that she has whatever she wants.

When I first started helping him, she was able to walk, talk. There were certain things she could say, and she could do little things for herself. But as the years went past she got to where she couldn't talk. She doesn't say one word. She used to say a few words, but she doesn't say anything. She used to move around in the house, tear things apart, put them back together, turn the gas on and try to make some tea. As the time went by he had to put extra locks on the doors to keep her from going out.

He doesn't have a family. It's just him and her. As time goes by, he has begun to get very worried about her and himself, because he's getting old too. He will not be able to take care of her because he has to bathe her, dress her, feed her, pull her up from her chair to go to the bathroom. She doesn't tell him when she wants to go or anything. We just have to figure these things out. It's just so ter-

rible. I know that he needs the relief.

My suggestion is that the caregiver get some relief. They need this help very much.

Senator BRADLEY. Well, thank you very much for your insight

and testimony.

Mrs. Jennings. Yes, we need this, because as I am with them, I share some of the things that nobody can understand unless it has hit close to them. It has to hit close to home for you to really understand it. You have to be with it every day.

Senator Bradley. Well, as the son of parents who are 89 and 81 and who cannot exist day to day without someone who does many of the same things that you do, I can assure you that I understand.

Mrs. Jennings. Thank you.

Senator Bradley. Victoria Hasser.

STATEMENT OF MS. VICTORIA HASSER, DIRECTOR, UNION HOSPITAL'S W.I.S.E. ADULT SOCIAL DAY CARE CENTER

Ms. HASSER. Yes. Thank you, Senator. I am Victoria Hasser, but

let the record show that I am also Vickie.

I am here representing adult day care, which is something that we haven't talked too much about in the introduction, but I know, Senator Bradley, that you are no stranger to adult day care. I was privileged to have attended the National Institute on Adult Day Care (NIAD) meeting in Washington recently and heard your presentation, demonstrating your commitment to adult day care. It certainly is something that is very important to us.

So let me tell you a little bit about Mr. Grimes' "school," as he

calls adult day care.

Adult day care is one of several respite options available in Union County. Union Hospital's W.I.S.E. Adult Social Day Care Program, which has been in existence since September 1983, has served over 500 clients during that time. At this moment we are

servicing 48 client members and their caregivers, some of whom are currently receiving SRCP funds.

W.I.S.E., W-I-S-E, is an acronym for Wellness, Independence, and Social Interaction for the Elderly. The acronym sums up the basic philosophies of the program: to keep its elderly members as physically, mentally, and emotionally well as possible; to keep them functioning independently; and to involve each member in meaningful and supportive social relationships. Above all, it is committed to the philosophy of preventing institutionalization where possi-

ble and for however long we can.

Under the supervision of the recreation therapist, members become involved in various activities, including arts and crafts, exercise, movies, trips, music, and discussion groups. Although many of these activities can be found in any senior citizens club, adult day care is a specialized program, designed for persons who are functionally impaired: persons with physical impairments, such as resulting from a stroke or arthritis; persons with cognitive impairments, such as Alzheimer's Disease; or persons with emotional problems, such as depression. They all greatly benefit from participation in adult day care.

In a professionally supervised individual and group structured programs, members can successfully involve themselves in rewarding activities that reinforce their self-esteem and sense of selfworth. Instead of being isolated in their homes, where a lack of physical, mental, and social stimulation may result in a deterioration in their functioning, members can remain active participants

in the business of daily living.

Adult day care also provides the caregivers of the elderly with much-needed respite. The stress of caring for an impaired person 24 hours a day can lead to physical and emotional exhaustion of the caregiver, making it difficult for the caregiver to cope effectively with his or her impaired loved one. This stress affects not only the primary caregiver but also frequently spouses, children, and even grandchildren, especially in the current multigenerational households and families that we're beginning to see more of.

Adult day care is indeed designed to serve whole families, not just the elderly client member. Having an elderly relative in a day care program for 6 to 8 hours a day, several days a week, can give a caregiver a chance to take a breath, put things back into perspective, attend to the needs of the other family members, and pursue interest of his or her own. Along with benefiting from the respite provided, caregivers can receive valuable information, counseling, and support from the professional staff of the program.

The social work staff keep well informed regarding community services and government entitlements available to adult day care clients, and they are well trained in handling the difficulties that

may arise from various functional impairments.

Perhaps the most important role of the staff is to be available to simply listen to caregivers and members, to provide a sounding board for their thoughts, their feelings, their concerns, and their fears.

Over the last several years, adult social day care has become an increasingly popular care option as we begin to acknowledge the older person's need for social stimulation and support. Home care services meet the physical needs of the elderly population, while adult social day care meets the equally important emotional and social needs of the elderly. At an average cost of \$35 a day, adult

day care is also a financially sound option as well.

Still, many persons in the community, especially those on a fixed income, find that they cannot afford to participate in the program. Through funding sources like the Statewide Respite Care Program, adult day care becomes an affordable care option. Currently there are 23 persons on the W.I.S.E. Center waiting list, with at least 80 percent of them eligible for SRCP support, we estimate. If you multiply those 23 people by two or more to include the caregivers and families in need of respite, and if you consider that there are many other such centers in the county, in the State, and, if you will, in the Nation, you will realize the sheer number of persons that could benefit from the SRCP program.

We urge you to continue to demonstrate your commitment to preventing the institutionalization of the frail elderly where possible. We heartily support your commitment to cost-effective, humane care options for the frail elderly, such as adult day care.

Thank you.

Senator Bradley. Thank you very much, Ms. Hasser, for your

testimony.

When you talk of adult day care, I have found so often, people don't appreciate how important it is. You find people with the green eyeshades saying, "Well, this will be abused," when in fact your point is that there are a number of people who are helped by adult day care, one of whom is the recipient of the care itself, but then there are the other family members. I visited an adult day care center up in Bergen County about 2 years ago, and a woman there told her story, which was that she was working as a secretary; she was a few years away from vesting in a pension plan; her husband got Alzheimer's; she had to quit her job, therefore lost her chance for a pension, and spent all of her time taking care of her husband. She had no way to make any money. They were just spending down all of their assets, essentially. If there was adult day care paid by Medicare for 100 days a year, at least that woman could have kept her job, could have gotten her pension, and could have provided her husband with a caregiver.

Ms. Hasser. Absolutely.

Senator Bradley. So I take it you would be supportive of my efforts to get 100 days of adult day care?

Ms. HASSER. Yes, I think you can count on that.

But I would like you to remember the social day care programs as well as the medical day care programs, the former unfortunately not included under Medicare Part B at this time. The adult social day care program equally meets the needs of many people in the community and provides the same kind of safeguards, allowing people not to be institutionalized, allowing people such as the secretary not to give up her job, and allowing caregivers to have some respite, as well.

Senator Bradley. The social day care? Ms. Hasser. Adult social day care.

Senator Bradley. That's the program where the individual is brought to a site between 9 and 4Ms. Hasser. Right.

Senator Bradley [continuing]. Like Mr. Grimes testified about? Ms. Hasser. Exactly. In fact, Mr. Grimes' relative is our client at the WISE Center. We happen to be a social day care program, and the services are really very extensive. It provides transportation and lunch and two meals and professional services.

Senator Bradley. I assume that all of the caregivers here would be supportive of efforts to renew the New Jersey Respite Care Pilot

Project?

Ms. Hasser. Absolutely.

Senator Bradley. And on the Home Health Care Improvement Act, extending the number of days of home health care from 21 to 38 days, I imagine for you, Ms. Ross, you would see the important value of that?

Ms. Ross. Oh, definitely.

Senator Bradley. And of course, on hospice, eliminating this 210-

day cap, you might speak to that, Peggy.

Ms. COLONEY. Yes. As the three members who have been involved in our program testified, it would have been very traumatic had their family members gone on, and they would have had to continue to somehow make whatever possible commitments they

had to the situation.

What we find, as far as the catastrophic bill was concerned, for the family members that had exhausted the 210 days, we continue the same. In our program we have that opportunity to do that because of our fundraising. But when we did our study and saw the patients that had exhausted that 210 days, and then still had needs that we were providing, they really didn't live that much longer. If we had not been able to continue the care at home we would have placed them into a hospital or a facility at a very, very trying time for this whole situation. After a family having gone through the whole journey of an illness with their loved one, and then maybe for the last week or so to place the patient into a hospital—which would have cost a great deal more money—or a nursing home, whatever the costs incurred, they would have been much greater than hospice.

So definitely, we would hope to see the catastrophic bill reinstat-

ed.

Senator Bradley. You would hope to have the cap eliminated? Ms. Coloney. Exactly.

Senator Bradley. Well, that's what we had until the law was repealed, as you know.

Ms. Coloney. Yes.

Senator Bradley. Which was a sad day, probably one of the sadder days since I've been in the Congress.

Let me ask you, Peggy Coloney, do you take care of terminally ill

children?

Ms. Coloney. Yes. We have no restrictions, really, as to disease entity, age. We are nonprofit, and I did want to say that we are nondenominational, too. The fact that Father Hudson is the Vice President of the Center sometimes leads people to believe that there is a denomination there. The Father is the Vice President, and the Center is nondenominational. We take care of AIDS patients and we take care of children. We also allow infusion, if it's

necessary, in the home. We use infusion for hydration. We allow infusion for antibiotics if it is prescribed by the physician, because hospice is symptom control, symptom management, palliative care. So whatever the physician who is the medical director of the program dictates, we allow that to happen.

Senator Bradley. So you would support reinstating certain intravenous drugs being used in a home setting when prescribed by a

physician?

Ms. Coloney. Yes, as opposed to having a patient go into the hos-

pital for that type of therapy, definitely.

Senator Bradley. Let me ask Mrs. Jennings just one thing, if I could.

From your experience, what difference do you think it makes to someone in just having someone to talk to? As I said, I have a parent who is 89 and one who is 81; they just celebrated their 50th wedding anniversary on Friday, so I was there. Here we had a perfect testimony to the value of having someone who comes in and just talks. They have someone who comes in and takes care of them, but at the same time, you might give us your own experience

Mrs. Jennings. Well, my experience with this man that I was helping, his wife doesn't talk. I think it gives him great pleasure to just sit and talk with me.

Senator BRADLEY. She can't talk?

Mrs. Jennings. She couldn't talk. She was there with—he just waited on her, bodily, but he had nobody to hold a conversation with. When I came in, he would be ready to go out for a little while. He would go out, maybe to the library or to the store to do a little shopping, but when he came back he would sit down and talk with me. He and I would talk, and he would talk about this situation. Sometimes it would be so stressing until he would even cry, so I knew he was having a real hard time.

It gave him pleasure to be able to talk to me.

Senator Bradley. So that your service was not only to the indi-

vidual who was sick, but also to the caregiver?

Mrs. Jennings. Right. One Sunday, he needed to get up. A relative from out of town came. I was only supposed to be working 3 hours a day, 3 days a week. Well, she came in on the weekend, and she wanted to take him someplace. I went and I spent the whole Sunday with his wife so that he could go into New York to see a play. That did him so much good. He said it had been years since he had had a chance to do that.

Senator Bradley. That's like the mother in Ocean County who once every other week had 6 hours on a Saturday to go watch her children play Little League baseball. That break that makes a difference for families is not appreciated unless you find yourself in that position, or unless you've been lucky enough to be a caregiver.

Let me thank all of you for your testimony. It has been very helpful, and I think it will help us as we deliberate on the bills that we have to consider. I would particularly welcome working with all of you in the days ahead.

Thank you very much.

Our last panel today consists of Diane Jones, who is Vice President and Legislative Co-Chairman, New Jersey Hospice Organiza-

tion; David Keiserman, Co-Legislative Chairman, New Jersey Chapter of the Council of Senior Citizens; and Pat Freeman of the Older

Women's League.

Let me welcome all of you. This is the last panel. I would hope that we would continue our efforts to be as brief as possible, and then respond to any questions. We are coming up against some time restraints here, so I will try to move the discussion forward.

Diane Jones, welcome to the committee. We would love to hear

your views.

STATEMENT OF MS. DIANE JONES, VICE PRESIDENT AND LEGIS-LATIVE CO-CHAIRMAN, NEW JERSEY HOSPICE ORGANIZATION

Ms. Jones. Thank you very much, Senator Bradley.

Mr. Bradley, members of the panels, members of the press, it is a pleasure to be here today and to have the opportunity to speak about issues that are of concern to the terminally ill Medicare and Medicaid beneficiaries and their families.

Let me first thank you, Mr. Bradley, on behalf of the New Jersey Hospice Organization—for inviting me here, of course, but most especially for the introduction of S. 2246, the Medicare Home Bene-

fits Act of 1990.

I would like to raise my voice in concern with those here today about the issue of waiving certain Medicare- and Medicaid-covered services when a terminally ill beneficiary elects the hospice benefit, particularly home IV therapy, home respite, and unrelated Medicaid services, such as attendant care.

Since their inception, hospices across the Nation have been committed to the notion that the goal of hospice care is to allow terminally ill patients to remain in familiar surroundings, either at home or in a nursing home, and to be cared for by loved ones until

they die.

The focus of care shifts from aggressive treatment to comfort measures and symptom management, most of which can be accomplished in the home. Caregiving shifts from high-tech institutions to the family or to custodial care institutions, and reimbursement shifts from traditional Medicare A and B to the Medicare Hospice Benefit.

Home IV therapy is an important part of your bill, but it overlooks hospices as providers of this service. The original Medicare hospice rate structure did not anticipate advances that would allow previously provided institutional services to be brought into the home. Even though Medicare beneficiaries who elect their hospice benefit are choosing not to pursue further aggressive treatment, IV therapy is sometimes required to manage the symptoms of the terminal illness, such as infections, dehydration, and pain control.

Currently, patients with these needs must be transferred to an acute care institution for treatment. This may mean that a patient dies in the institution rather than at home, thereby denying the caregiver the realization of achieving the primary goal of hospice.

This may also mean that the patient is denied the right to remain at home and to avoid further hospitalizations. Medicare beneficiaries should not have to waive this service, and hospices should not have to bear the high cost of either providing home IV therapy, or refusing patients and their families the desire to remain at home.

Home respite care is also covered by your bill, and again, hospices are not named as providers. You have certainly recognized the importance of home respite for those chronically ill Medicare beneficiaries being cared for at home by their loved ones. The underlying rationale for this service must certainly extend to cover the terminally ill Medicare beneficiary, as well.

Currently, the only way the primary caregiver of a terminally ill patient may obtain much-needed rest is to institutionalize the patient for a short period of time, generally in a nursing home. Not only are caregivers extremely reluctant to move their loved ones, but nursing homes are very averse to short-term admissions. Hospices simply can't find adequate respite beds in the community.

Home respite care is an entitlement that should be available to the chronically ill and the terminally ill alike. It meets the goal of avoiding unnecessary hospitalizations due to an exhausted caregiver with no other viable recourse, and it underscores the important fact that hospices, in order to be utilized appropriately and effectively, must not be perceived as alternatives to health care, but rather as providers of health care.

Attendant care was designed to help the Medicaid beneficiary avoid institutionalization by providing hands-on assistance in the home. The parameters of this service have been clearly defined through the careful design of needs assessments and other screening devices. The targeted group, the neediest among us, remains unchanged, and its needs do not diminish with the additional burden of a terminal illness.

It is imperative that the duly eligible Medicare-Medicaid beneficiary not be required to forgo this or other Medicaid services clearly unrelated to the terminal illness, and this mandate must come from the Federal Government.

Mr. Bradley, S. 2246 is a notable and worthy bill. Hospices across the Nation applaud the inclusion of the fourth benefit period that was eliminated with the repeal of the Catastrophic Coverage Act, and we in New Jersey are particularly proud that you have presented such a bill. Your interest in health care and your caring for older and chronically disabled Americans is indeed evident.

We believe that hospice is a special and unique kind of caring, and we ask that you support that perception by naming hospice as

a provider for home respite and home IV therapy.

Access to these services translates into opportunities for making the right decision for the right reasons.

Thank you.

Senator Bradley. Thank you very much, Ms. Jones.

Mr. Keiserman.

STATEMENT OF MR. DAVID KEISERMAN, CO-LEGISLATIVE CHAIRMAN, NEW JERSEY CHAPTER OF THE NATIONAL COUN-CIL OF SENIOR CITIZENS

Mr. Keiserman. Good afternoon Senator Bradley. My name is David Keiserman, and I want to thank you for this opportunity to present the views of the 250,000 members of the New Jersey Council of Senior Citizens.

I am sure that you are as unhappy as we with the Pepper Commission's report. It was you who amended the Senate's Medicare Catastrophic Protection Act to establish this commission. Although many worthwhile recommendations have been made by this commission, no funding or new legislation is expected until God knows when

Meanwhile, we feel there are several programs that are proving to be not only cost-effective, but are also improving the quality of life for the elderly. Common sense demands that we expand these programs for the betterment of the patient and to lower costs. Some of the programs that need expansion or improvement are:

One, the hospice care program—by limiting hospice care to two 90-day periods and a 30-day period—and by the way, that doesn't always add up to 210 days, Bill. Surprisingly, if you have to have a break in a period to go into a hospital for any reason whatsoever, you lose the rest of that period. So if you go into a 90-day period but only use 10 days, you lose 80 days out of that 210. I don't know if that's been done administratively. I'm sure that wasn't in the legislation. That's something you should look into.

If the patient is hospitalized during a period, he or she loses the balance of the period unused. A terminally ill person has no recourse other than to stay in a hospital, sometimes. We must end

these limitations.

In the respite care program—relief is limited to only 80 hours a year under the Federal program. These other programs are not Federal programs that are funding some of the respite care. The Federal program is still limited to only 80 hours a year to a family or a friend who is the caregiver. With more than 50 percent of all home health care being provided by the family or friend, with care sometimes being needed for 24 hours a day, 7 days a week, too many caregivers are forced to give up. Institutional care and Medicaid are the results.

Expansion of the respite program to cover day care centers, training for the caregiver—that's another thing we need and we must strive for. If the caregiver could get some training, it could make the job a heck of a lot easier for that person, and that's something that can be done very reasonably and could help tremendously. More relief hours would make life much better for both the pa-

tient and the caregiver, and could be very cost-effective.

Now, under acute care, we must end the 3-day hospital stay requirement for a person to be eligible for skilled nursing care. With modern drugs, even home intravenous treatment is now possible. Patients can now be given acute care in skilled nursing facilities and even in the home without first having a costly hospitalization period. We need to broaden our views and realize that the rules that we found necessary a few years ago are now placing costly restrictions upon more efficient ways to care for our sick and frail citizens.

Thank you for granting me this time to present the views of the members of the New Jersey Council of Senior Citizens. We would also like to express our thanks for your many efforts in advocating programs for the elderly and for the leadership you have shown in our behalf.

Senator Bradley. Thank you very much, Mr. Keiserman.

Pat Freeman.

STATEMENT OF MS. PAT FREEMAN, OLDER WOMEN'S LEAGUE

Ms. Freeman. I am Pat Freeman, Secretary of the Monmouth County Chapter of the Older Women's League, the first national membership organization focused exclusively on the concerns of midlife and older women.

Support services for caregivers has been a key item on OWL's national agenda since its founding 10 years ago. Our primary concern has been for unpaid caregivers—wives, daughters, daughtersin-law, and sisters who care for chronically ill family members, but we have become increasingly concerned with the plight of paid

caregivers to the elderly, 90 percent of whom are women.

According to the Older Women's League 1989 Mother's Day report, "Failing America's Caregivers: A Status Report on Women Who Care," for the first time ever American women are spending more time caring for dependent parents than for children, and millions spend additional time caring for frail or sick husbands, brothers, and other relatives. Lou Glasse, President of the Older Women's League, remarks that "the empty nest is an anachronism. If nests empty at all they fill up very quickly." The report goes on to say that elder care is expected to be a major crisis in this decade and beyond.

It is a myth that families are sending their parents or spouses to institutions for care. Only 5 percent are institutionalized. Nine in ten of the disabled elderly not in nursing homes receive unpaid care from relatives and friends. Thirty percent of caregiving wives are over 74, and in precarious health themselves. Another 1.8 million fall into the "sandwich generation" and must juggle caring for

elderly parents while still raising their own children.

Many struggle to hold onto their jobs, but are finally forced to make an agonizing choice between paid work outside the home and unpaid caregiving. For midlife and older women, the economic consequences of leaving paid employment can be devastating. They often must forfeit health and retirement benefits along with their jobs, and then, to top it off, when computing their monthly retirement benefits, Social Security adds a zero for each year women spend out of the workforce.

Ninety percent of the paid caregivers to the elderly and children are women, disproportionately minorities, receiving little training, and most earning just above the minimum wage. Less than 50 percent of nursing aides have health insurance, and less than one in

five has pension coverage.

Anecdotal reports show an even worse benefits picture for health aides and child care workers. The women who bathe, feed, dress, and care for parents and children earn less than zookeepers or

parking lot attendants.

In its report, OWL calls for a series of legislative reforms to address the problems caregivers encounter. The recommendations are much broader than the legislation which we are considering this afternoon, but this legislation is a step in the right direction. We look forward to that legislation extending a very successful New Jersey Respite Care Demonstration for 2 more years. For the caregivers who were served by this program, it has been a Godsend.

The Medicare Home Benefits Improvement Act will allow Congress to provide some very important benefits that were lost when the Catastrophic Coverage Act was repealed. Eighty hours of respite care a year doesn't seem like much, but it could add up to an hour a week to shop without worry, an annual vacation, or time to attend a play or visit a friend.

If intravenous drugs can be safely administered at home, it seems ridiculous to keep a patient hospitalized in order to administer daily doses. Medicare should cover administration of these

drugs in a home setting.

If every terminally ill patient died within 210 days, we could be satisfied that the present limit for hospice care coverage is sufficient, but the fact is that some patients die in 2 weeks, others in 2

years. There should be no time limit on hospice care.

Last summer, one of our chapter members was told that she had cancer of the pancreas and that she wouldn't live until the end of the year. She became very depressed. Her family, friends, and even a psychiatrist couldn't help her. Her primary caregiver, an 85-year-old sister, didn't know where to turn. The doctor put them in touch with hospice. Gradually, she began to deal with her imminent death. She sought spiritual counseling, and called the hospice nurse her "angel." The quality of her life and that of her sister improved significantly. But the cancer didn't move as quickly as expected, and she left the hospice program for a while on the advice of her nurse in order to save some time for the end when she would need it the most.

The end came for her last Wednesday night. The hospice nurse

who had prepared her for death was with her when she died.

Should terminally ill patients be denied continuous hospice care

because they don't die within 210 days?

Along with the New Jersey members of the Older Women's League, I urge you, Senator Bradley, to continue your fight for home care services for the long-term care needs of the elderly.

Thank you.

Senator Bradley. Thank you very much, Ms. Freeman, for your

testimony.

Let me thank the whole panel for your suggestions. I think there are a number of positive and very good suggestions. I just have one or two questions.

For Ms. Jones, does your organization provide for terminally ill

children as well as the elderly?

Ms. Jones. Yes, we do.

Senator Bradley. Are there any differences in the needs of families when you talk about a terminally ill senior citizen versus a ter-

minally ill child?

Ms. Jones. The dynamics certainly are different. Terminally ill children have a much more frequent need to be hospitalized. I think that that's probably the primary difference. Even though the child might be terminally ill, the perspective of hope is a little bit different than with the terminally ill elderly person. The possibili-

ty of reversibility for some of those symptoms takes on a different kind of meaning when you're talking about a child.

Senator Bradley. The chances that it's the one in a million that

doesn't die takes on greater significance.

Ms. Jones. It takes on much greater significance, that's right. And also, the kind of time that the child has left and the ability to reverse some of the symptoms for a longer period of time.

Senator Bradley. But then you ultimately are left with trying to help the family cope with the fact that their child is about to die?

Ms. Jones. That's right.

Senator Bradley. A few months ago I was in a hospital in Newark, and we went into one of the AIDS wards. There was a 9year-old kid who was surrounded by books and dolls and so forth, and the doctor said, "He's going home next week, to die," because there was nothing more that could be done in the hospital.

Ms. Jones. Hospice has the ability to facilitate the transition between hospitalization and home care, and can provide the continui-

ty that is needed for the family or the child.

Senator Bradley. Mr. Keiserman, you and the Council do sup-

port the extension of New Jersey Respite Care?

Mr. Keiserman. Definitely. I would support it. We advocate it very strongly.

Senator Bradley. I just wanted to double-check on that.

Mr. Keiserman. I didn't think I left any doubts in my testimony. Senator Bradley. Ms. Freeman, I wonder if you could deal with the question with which we in government are frequently confronted when we are suggesting that there is a benefit that has not been provided that should be provided, and that problem and charge is that "Well, if you provide this benefit, people are going to come out of the woodwork," and that the estimated cost is going to be much greater than was anticipated.

Do you have a response to someone who makes this kind of

charge? I have my own response.

Ms. Freeman. This country is in the middle of a health care crisis right now and we have to address it. We actually have a crisis in the savings and loan, and we address that. Why is this less important? Why are people less important? Why are American

families less important?

Caregiving is not an elderly problem. The elderly problems aren't their own problems. They are the problems of the families, as the children's problems are also the problems of the elderly. We care about taxes, we care about AIDS, we care about education—as our children care about us. We are part of the American family, and it is time that we have to address these issues. We have to bite the bullet, do something about it, raise taxes-read my lips: raise

Senator Bradley. I think that your point really did come through in this hearing today, that when you provide care for an elderly person, the beneficiary is not only the elderly person, but in so many cases it is other family members as well as your own selfrespect and self-esteem.

I frankly want to thank all of you for coming and testifying today. I have been deeply moved by the depths of your own compassion and the resolve that you have to care for a loved one or for a client. I come away from here more convinced than ever that this network of support really should be deepened and broadened, and it is with that in mind that I will continue my efforts to eliminate the cap on the 210 days, and I hopefully will be successful in extending the New Jersey Respite Care project for another 2 years, and the Home Benefits Improvement Act, which would almost double the number of days of home health care, provide for the intravenous drugs, and provide 80 hours of respite, as you say—not a whole lot, but it is an important beginning, and in a few families' lives, it makes all the difference. I would also hope that we could get the adult day care bill passed.

So those are my objectives, and I think the hearing today has really given me even deeper information and stories that would make my effort, I would hope, successful. I think that as human beings we owe it to each other not only to be kind, but to be caring,

and that's what these bills attempt to do.

So I want to thank all of the witnesses for testifying. I think you've done a fine job today. I ask your continued support of these efforts, and I would love to be kept informed of your progress as well as your needs.

So thanks, everyone, for coming, and the hearing is adjourned. [Whereupon, at 2:45 p.m., the committee was adjourned, to reconvene at the call of the Chair.]

APPENDIX

Item 1



ROSEMARY CUCCARO, R.N., B.S., M.A. Executive Director

354 UNION AVENUE • P.O. BOX 170 • ELIZABETH, NEW JERSEY 07208 • PHONE: 201-352-5694

TESTIMONY FOR SENATOR BRADLEY'S HEARING HELD IN ELIZABETH, N.J. ON June 18, 1990.

My name is Shirley Altman and I am the Administrator of Visiting Nurse and Health Services Hospice.

First, Senator Bradley, let me thank you for coming to Union County to allow us to express our concern for our Hospice patients. Having attended the hearing, I want to change the misconception that there is only one Hospice serving the residents of Union County, In fact, there are five Hospices dedicated to improving the quality of life for the terminally ill and their

Our Hospice developed out of the Visiting Nurse and Health Services which has been serving the residents of Union County for 78 years. The same dedication that has been the moving force for our parent agency exists in our Hospice.

We were deeply concerned when the 210 day cap was once again placed on our Medicare Hospice patients. While the majority of patients die within several months, there is the occasional patient that lingers on. The limit of 210 days makes many physicians reluctant to sign their non-cancer patients onto Medicare Hospice, thus denying the terminally ill cardiac or lung disease patient the benefits of the program.

The decision to place a patient on Hospice is never made lightly, thus we keep patients on our home care program until the physician, patient and family are ready to face that ultimate fact, that death is imminent. Since all payments remain under the cost cap, there is also a control that the additional days will not be abused.

We never deny care to a patient because of lack of payment, however, since we loose money on the patients who die within the 210 days; it is a severe hardship to continue care to those who outlive the benefit.

I would also like to mention that the gentleman who testified that benefit days were lost should a patient be hospitalized, is mistaken. As I am sure you know, the days in the hospital are counted as part of the 210 days.

As a health care provider, I wish to express my gratitude for your concern for and knowledge of the needs of the terminally ill in our society.



AREAS SERVED:

United Way A United Way Agency

Clark, Cranford, Elizabeth, Fanwood, Garwood, Hillside, Kenilworth, Linden Mountainside, Rahway, Roselle, Roselle Park, Scotch Plains, Springfield, Union, Vauxhall Westfield, Winfield and other Union County Municipalities Item 2

137 Washington Avenue Elizabeth, N.J. 07202 June 8, 1990

The Honorable William W. Bradley Hart Office Building Room 731 Washington DC 20510

RE: State Respite Care Program Union County, N.J.

Dear Senator Bradley:

I would like to take this opportunity to commend the Respite Care

Program for the excellent care my wife has received from this organization.

I had been solely responsible for the care of my wife since she striken ill, and the burden was taking a toll on my health. But, now with the aid of a homemaker, I am able to go to work knowing she is in good hands.

Once again, I wish to express my heartfelt appreciation for the Respite Care Program.

Frank Izzo

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