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# RESPITE CARE: REST FOR THE WEARY

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**HEARING**  
BEFORE THE  
**SPECIAL COMMITTEE ON AGING**  
**UNITED STATES SENATE**  
**ONE HUNDRED SECOND CONGRESS**  
FIRST SESSION  
—  
**WASHINGTON, DC**  
—  
APRIL 23, 1991  
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## RESPIRE CARE: REST FOR THE WEARY

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TUESDAY, APRIL 23, 1991

U.S. SENATE,  
SPECIAL COMMITTEE ON AGING,  
*Washington, DC.*

The committee met, pursuant to notice, at 2:50 p.m. in room 628, Dirksen Senate Office Building, Hon. Bill Bradley (acting chairman of the committee) presiding.

Present: Senators Bradley, Kohl, Sanford, Cohen, Pressler, and Durenberger.

### OPENING STATEMENT BY SENATOR BILL BRADLEY, ACTING CHAIRMAN

Senator BRADLEY. The committee will come to order.

Our hearing today is a very important one. We will be receiving testimony from a number of individuals who have their own personal experiences to share with the committee, as well as testimony from very knowledgeable professionals about the benefits of respite care and respite programs. When you leave the hearing today, I'm sure that you will have gained a better understanding of the plight of the caregiver and the additional pressures facing our families today and tomorrow.

We are aging in America. Today, 32 million Americans are age 65 and over. Current Census Bureau projections predict that the number of people over age 65 will increase to nearly 57 million, and that those 85 and over—the frail elderly and fastest growing segment—will represent approximately 8 million by the year 2020. In 20 years from now, nearly 1 person in 7 will be over the age of 65.

Some of our greatest medical advances have prolonged and improved the quality of life for our aging and disabled citizens. Our study of the infant mortality problem has shown that medical technology is responsible for a significant portion of the recent decline in our national rate of infant death, but often these saved infant lives result in significant disabilities in children.

Usually, when people think of the aging and the functionally disabled, a depressing image of nursing homes that are overcrowded and understaffed comes to mind. Although the ranks of the institutionalized elderly and disabled are growing, nursing homes make only a small contribution to long-term care. Four out of five Americans with functional disabilities are cared for not in institutions, but by family members at home. Family caregiving, as you will hear today, requires enormous physical and emotional energy.

Throughout the years I have grown increasingly sensitive to the value of the informal network of loving family caregivers. I see it as the embodiment of family values and the backbone of every community's effort to offer the humane and dignified care, and maintain the quality of life for its frail and disabled citizen. This family care is not without its cost in increased stress and strain on the family and on the primary caregiver in particular.

The American family is changing. There are fewer children, older first-time parents, both parents working outside the home to sustain the family, and more grandparents are living longer and require more family support as their dependency increases. We will hear testimony today about this so-called sandwich generation.

If we as a Nation are to have any effective long-term care strategy, it will have to build on and support this valuable network of family caregivers. The fear of disability and dependency can be softened by the love and care of one's family. The primary family caregivers can and should be bolstered and supported in their desires to keep their loved ones at home and/or in the community. Often a minimal amount of respite—time out from the unremitting task of providing for basic human needs—is enough to prevent the disintegration of the family unit or the personal health status of the primary caregiver.

I asked the Aging Committee to schedule this hearing so that the Senate could learn more about how these programs work from those who are most responsible for making them work. I am committed to the maintenance and empowerment of the American family. This is clearly one of the most critical issues facing that unit in the coming decade.

Senator Cohen.

#### OPENING STATEMENT OF SENATOR WILLIAM COHEN

Senator COHEN. Thank you very much, Mr. Chairman. I'd like to begin by first paying tribute to the man whose chair I now occupy, our good friend and former colleague, Senator John Heinz. John's chair as the ranking Republican member of the committee is going to be hard to fill. As most of you know, he was a tireless champion of issues affecting the elderly. While all of us have been greatly enriched by his presence on this committee over the years, we're going to be deeply impoverished by his absence now.

I first joined the Aging Committee in the House of Representatives back in 1975, the first year that it was formed. Claude Pepper was the chairman of that committee. John and I served on that committee together and it was a memorable experience.

I think at one of our first public hearings we had Will Geer called as a witness. Grandpa Walton came to the table and he said, "A man or woman's got to have a table to pound. If you take that table away, you take away that person's reason for living and zest for life." So, he always wanted a podium at which to bring before the committee the issues that affected him and his generation. It was very moving testimony that he gave that day and I think that it inspired the committee. Claude Pepper went on, as you all know, to truly become the champion of the elderly.

I want to commend Senator Bradley—who also is aging by the way—the Senior Senator from New Jersey—[laughter]—because this is a very important issue and it's important that he bring it before the committee. I know of his dedication and commitment to the respite care issue. As he has mentioned, caregiving by those who remain in the home is a very stressful occupation. It's fatiguing, it is unrelenting, and there is a need for temporary respite or relief.

President Bush, in deciding whether he is going to sign a child care bill, has been concerned about those people who choose to remain in the home, saying, "shouldn't they be given some consideration for staying home and taking care of their children as opposed to going to work and putting their children under some sort of 'institutional' care for the day, like a day care center?" Many of us said, "That's right. There are people who make sacrifices to stay home and they should be looked after, as well, when we adopt a child care proposal."

Similar rationale applies here to ensure that those people who choose to care for their parents or grandparents in the home so that they will not be forced into an institution when it's either unnecessary or unwanted, have some measure of relief.

My own State of Maine was one of the first States to adopt a program at the local level to provide respite for people who make that kind of sacrifice. It has enabled thousands and thousands of parents to take care of their grandparents, and children to care for their parents.

So I hope, Senator Bradley, that as a result of these hearings we will be able to develop a consensus, certainly on the committee, but hopefully in the Congress, on legislation along the lines that you have suggested.

[The prepared statement of Senator Cohen follows:]

#### PREPARED STATEMENT OF SENATOR WILLIAM S. COHEN

Mr. Chairman, I would like to begin by paying tribute to the man whose chair I now occupy, our good friend and colleague, Senator John Heinz.

John's chair will be difficult to fill. His stature among those involved in aging issues is legendary, and his compassion and commitment to the work of the Special Committee on Aging unmatched. John was a tireless champion of our nation's elderly, and, just as we were greatly enriched by his presence, we are impoverished by his absence. He will be sorely missed.

I would also like to note that we are encouraged by reports of the continued improvement of Senator Pryor and send him every wish for a speedy recovery. We miss him this afternoon and look forward to his return.

Senator Bradley is to be commended for bringing this issue before the committee this afternoon. While the need for respite care is but one aspect of the greater long-term care problem, I look forward to hearing from our witnesses about ways to ease the burden for families caring for elderly or disabled relatives in the home.

When most Americans think of long-term care, the image of a nursing home immediately comes to mind. However, nursing homes play a relatively minor role in our nation's long-term care delivery system. Today, four out of five Americans with physical or mental disabilities are cared for by family members at home.

These family caregivers devote enormous amounts of time and energy to provide often round-the-clock care to frail or disabled loved ones. Given the high levels of stress and fatigue entailed, this caregiving burden often threatens to become a significant health care issue of its own. Unfortunately, a service sorely needed by family caregivers—respite care—is often not available.

Respite care offers scheduled time off for the family caregiver. It provides a measure of relief and an opportunity for the caregiver to meet personal needs. Respite care settings and programs may vary. Care can be offered in the patient's home, in

a day care center, or in a residential setting. While the recipient of the care may be the patient, the primary beneficiary of the service is the family caregiver.

My home state of Maine was one of the first to allocate state funds for home-based services designed to provide a degree of relief for family caregivers. These services have effectively enabled thousands of Maine families to continue to care for parents and/or grandparents who would otherwise be placed in a nursing home.

Mr. Chairman, as I noted earlier, respite care is but one aspect of the number one health issues facing older American's long-term care. Most of us agree that both public and private coverage for long-term care should be expanded to protect individuals and their families from potentially devastating costs. The challenge facing Congress is to find an acceptable and appropriate way to pay for it, and I look forward to working with my colleagues on this committee to build the consensus necessary to achieve significant long-term care reform.

Senator BRADLEY. Thank you very much, Senator Cohen.  
Senator Kohl.

#### OPENING STATEMENT OF SENATOR HERB KOHL

Senator KOHL. Thank you very much, Senator Bradley.

We appreciate you bringing us together to learn more about the struggles of these families. I particularly would like to welcome the Wisconsin representatives from the Alzheimer's Association who are in the audience today.

When it comes to caregiving we have an incredible resource in the family; but the trends of the last couple of decades are disturbing because our social policies sometimes drive families apart. Sometimes they make it difficult for families to provide the love and care and kinship that is such a healer to us all.

Ask just about any older person you know what their greatest fear is. Almost always, it is dying in a nursing home. Ask just about anyone what they want to do for their parents. You'll find that what they want to do is all they can to make their parents happy, they want them to be able to live in dignity, surrounded by loved ones. Respite for these children and parents is vital.

Just for example, I received a letter from Laura Horvat of West Allis, WI. Her mother has Lou Gehrig's disease, and her father has Alzheimer's. She cares for both parents at home. To handle those responsibilities, she had to switch from a full-time job to a part-time job.

Mrs. Horvat does not ask for much. She needs a little time and a little help to keep her parents at home, were they want to be.

She wrote:

I don't want to see my parents in a nursing home. Why send them there when they can enjoy life here, with their new home and family? We need programs to help us and others. Someday you or I, or someone else close to us, will need help.

Respite care can help Mrs. Horvat, and millions of other Americans who are bearing the huge financial and emotional costs of caring for their loved ones. It helps families stick together. It relieves the burden on "sandwich families," where middle-age women and men care for their parents and their children. So I hope this hearing will make it clear that respite care is both cost-effective and needed, and I look forward to the testimony of our witnesses.

Senator BRADLEY. Thank you very much, Senator Kohl.  
Senator Pressler.

## OPENING STATEMENT OF SENATOR LARRY PRESSLER

Senator PRESSLER. Thank you very much, Mr. Chairman. I shall place much of my statement in the record, except to add that I think it should be our goal to recognize people who stay in their own homes and receive care. Home health care actually saves the taxpayer money, as opposed to having these people in nursing homes. Anything we can do to encourage families to care for the elderly in their own homes is something we should be doing.

This morning I attended the public policy forum of the Alzheimer's Association. Home health care services are particularly essential for individuals with Alzheimers. If we just conclude that everybody who needs care has to be institutionalized, it will be much more expensive for society.

Also, I think it is very important that we recognize the dedication of those involved in respite care services. Caregiving is a very difficult task. It consumes a great amount of physical, emotional, and financial resources. Whether the family member is mentally or physically impaired, or simply elderly and in need of assistance, the caregiver's job is never easy. I commend the caregivers who are here today and who are going to be testifying, for their dedication in serving the needs of loved ones.

South Dakota, my State, has a well-established respite care program. During the last fiscal year respite care services were provided to 285 clients. Of this figure, 20 percent of the client-base had Alzheimer's disease. Although there are no income qualifications for service, approximately 60 percent of these are low-income individuals. In South Dakota's program, 140 organizations provide a total of 61,000 hours of care annually.

Of persons over age 65, 95 percent live at home and 35 percent of caregivers to the elderly are also over the age of 65. In addition, three out of four caregivers are women. As our elderly population continues to grow at a rapid rate, it is essential that we recognize the particular needs of this segment of our population.

I look forward to hearing from the witnesses today. I hope that through the hearing process we can gain some insight into ways to improve respite-care services. In recognizing the special need of caregivers, we can begin to strengthen and support their good work and identify some possible means of providing relief to them.

Thank you, Mr. Chairman.

I have some additional material for the record.

[The prepared statement of Senator Pressler and the additional materials submitted for the record follow:]

### PREPARED STATEMENT OF SENATOR PRESSLER

Mr. Chairman, I am pleased that we are examining respite care services today and, under the unfortunate and unforeseen circumstances, I especially thank you for taking the time to chair today's hearing. It is essential that respite care services be made available to caregivers who provide full-time care to family members. Caregiving is a very difficult task. It consumes a great amount of physical, emotional and financial resources. Whether the family member is mentally or physically impaired or simply elderly and in need of assistance, the caregiver's job is never easy. I commend the caregivers who are here today for their dedication in serving the needs of their loved ones.

It is particularly appropriate that this hearing was arranged to coincide with the Alzheimer's Association's 1991 Public Policy Forum. Alzheimer's disease places a



difficult burden on caregivers. It weakens both mind and body. In most cases, neither public programs nor private insurance provide protection for afflicted families.

Two of the witnesses here today, Mrs. Spadaro and Samuel Kaplan, provide care for a family member with Alzheimer's disease. In Mr. Kaplan's words, "... it's only the caregivers that truly understand what the daily routine of caring for a fully-grown adolescent is really like." It is indeed a difficult task to watch a spouse or loved one regress so dramatically.

Since 1985, South Dakota has had a well-established respite care program. During the last fiscal year, respite care services were provided to 285 clients. Of this figure, 20 percent of the client base had Alzheimer's disease. Although there are no income qualifications for service, approximately 60 percent of the clients are low-income individuals. In South Dakota's program, 140 organizations provide a total of 61,147 hours of care annually.

Ninety-five percent of persons over age 65 live at home, and 35 percent of caregivers to the elderly also are over age 65.

In addition, three out of four caregivers are women. As our elderly population continues to grow at a rapid rate, it is essential that we recognize the particular needs of this segment of our population.

I look forward to hearing from the witnesses today. I hope that through the hearing process, we can gain some insight into ways to improve respite care services. In recognizing the special needs of caregivers, we can begin to strengthen support for their good work and identify some possible means of providing relief to them.

**Senator BRADLEY.** Thank you very much, Senator Pressler.

Before we begin I want to insert the statements of Senators Shelby, Grassley, Simpson, and Sanford.

[The prepared statements of Senators Shelby, Grassley, Simpson, and Sanford follow:]

#### PREPARED STATEMENT OF SENATOR RICHARD SHELBY

I want to thank my colleague, Senator Bradley, for requesting and consequently acting as chairman of this hearing. The issue of respite care is so important. The title given to today's hearing, "Respite Care: Rest For The Weary", says it all. With at least 32 million Americans age 65 and over, and with the predictions that the number will increase to 57 million, we must find a way to provide some sort of "rest for the weary".

My interest in this issue is heartfelt. As I have traveled across Alabama during my years in the Senate, holding town meetings and just visiting with Alabamians, the fear and distrust in this nation's healthcare system becomes more apparent. People are afraid. They are afraid that illness will strike and they will not be able to cope. I am not referring to being able to cope emotionally. I am talking about being able to cope financially. The elderly are concerned for themselves. The middle aged are concerned for their parents, and as the aches and pains of age sneak up on them, they are also concerned for themselves. The young people in this country seem to me to exhibit a cynical view of this nation's strained healthcare system, and an even gloomier perception of what Congress is going to do about the problem of spiralling costs.

I do not mean to imply that the standard and quality of our healthcare is surpassed by any other nation on earth. It is not. We have the finest minds and most skilled men and women providing healthcare and laboring in our laboratories. However, we seem to be missing the point when it comes to that step that now seems inevitable for so many aging Americans—requiring family care at home.

I have read the testimony of a number of our witnesses today. I was especially interested in the facts, figures and common sense as applied to the number of Alzheimers patients who are and will be receiving care at home. The answer seems so simple—respite care. Respite programs—however they may be tailored to meet a family's specific needs—seem logical and humane. I hope we can move closer to meeting this need.

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#### PREPARED STATEMENT OF SENATOR CHARLES E. GRASSLEY

Thank you, Mr. Chairman, and thank you for suggesting this hearing on respite care—a very important topic to all of those interested in how our society cares for people with long term care needs.

Before I begin I just want to say that I am thankful that Senator Pryor will be out of the hospital soon, and, I hope, back soon with the Senate. I was very concerned, as we all were, when I heard that he had had a heart attack. But at least we know he is out of the woods and recuperating.

Mr. Chairman, I think most of the members of this committee are familiar with what respite care is, and probably understand how terribly important it is to those who are taking care of dependent family members.

We are perhaps most familiar with this because of the considerable attention which Alzheimer's disease has received in recent years.

My legislative experience with this comes mainly through this committee and through my chairmanship of the Subcommittee on Aging of the Senate Committee on Labor and Human Resources. Our subcommittee reauthorized the Older Americans Act Amendments of 1984 and included in that reauthorization several provisions designed to improve respite care for families of Alzheimer's disease victims.

And the Alzheimer's Disease and Related Disorders Research Act of 1986, which I sponsored with Senator Metzenbaum and which became law while I was chairman of that subcommittee, had several such provisions also.

But it is not just Alzheimer's disease which places families in the position of having to care for a dependent family member. Strokes, cancer, disabling injuries, can all cause disability and dependence on others.

And it's not just the elderly who can find themselves dependent on family members. People of any age, really, can become dependent on them.

As I understand it, something like four out of five Americans with physical or mental disabilities are not cared for in institutions, but by family members at home.

One of the things I learned in my work on Alzheimer's disease over the years is how important respite care can be to a family, often a single individual, and more often than not a woman, who may be old herself.

Respite care is important because caregiving is *stressful*. I understand it is now possible to document that those experiencing the stresses of caregiving can actually have a deterioration in their immune response, thus becoming themselves more vulnerable to sickness. In many cases, caregiving calls for just about total commitment of the time, energy and emotion of the caregiver. It can be very expensive. It can be complicated and it can be frustrating.

Having some regular relief from the rigors of taking care full time of a dependent family member may be the only thing keeping the individual being cared for in the home and in the family, rather than being consigned to an institution.

With that I will stop, Mr. Chairman. I am looking forward to our testimony today, and to reviewing the legislation our chairman for today has introduced, and the legislation my colleague on this side of the aisle, Senator McCain, has introduced.

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#### PREPARED STATEMENT BY SENATOR ALAN K. SIMPSON

I am pleased to attend this hearing on respite care services. We are all here today because we recognize that this is a critically important health care issue which deserves the attention of Congress.

It is a difficult and troubling experience to have a family member dependent and unable to perform life's basic activities. I have witnessed that firsthand with my dear old dad who is laboring along in his 93rd year. His quality of life has seriously diminished in recent years. It is a sad thing to watch.

Family caregivers perform a herculean task, and many of them do it 24 hours a day, 7 days a week, 52 weeks a year. It is most unfortunate that we have not been able to devise a long term care system that meets all of the needs of the frail elderly. It is an economic and demographic reality that we must find a way to accommodate the needs of this growing segment of our population.

I look forward to reviewing in greater detail Senator Bradley's proposal for "family caregiver support." This bill appears to be a thoughtful and reasonable approach to solving a very complex problem. Still, as with any new proposal, we must give careful consideration to the cost of this solution. That is a reality we are forced to consider in this era of tight budgetary constraints—not just with regard to health care issues, but with every aspect of government.

All of us are sensitive to the fact that entitlements are consuming an increasingly larger share of our government's resources. Although Senator Bradley's bill calls for a "capped" entitlement, there will inevitably be pressure for an expanded and more generous program. It may be that this is what is required. I certainly intend to give this proposal my most thoughtful and serious consideration. But I also want to make sure that it results in a cost-effective use of our health care dollars. Our gov-

ernment's present fiscal condition demands that every program meet that important requirement. The present debt of the United States is almost three and a half trillion dollars, and the "debt limit" has now been extended to \$4,145,000,000,000.

Again, I want to emphasize my deep personal interest in finding a remedy for the difficult problems encountered by family caregivers. Our presence here today is clear evidence of this committee's commitment to finding such a solution. I want to offer my thanks to Senator Bradley for his thoughtful proposal and I look forward to hearing the testimony from this fine panel of witnesses. I trust that the findings of this hearing will assist us as we work to achieve a solution to these vexing problems.

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PREPARED STATEMENT OF SENATOR TERRY SANFORD

First of all let me just say that I am pleased to be a new member of the Senate Special Committee on Aging. I look forward to working with committee members on the many important issues like the one before us today, respite care, that will be addressed here during the coming years.

This is the first opportunity I have had to participate in the work of the Special Committee on Aging, and I am especially pleased to have a representative from Duke University participating in this hearing today.

Lisa Gwyther is Director of the Family Support Program at the Duke Center for the Study of Aging and Human Development and also the Education Coordinator of the Joseph and Kathleen Bryan Alzheimer's Disease Research Center at the Duke University Medical Center.

Since its inception in 1955, the Duke Center for the Study of Aging and Human Development has become the oldest continuously funded Center in the United States. The Center's programs have evolved from an initial concentration on longitudinal studies of normal aging and psychosocial and behavioral aspects of aging, to a broadened emphasis, including a strong focus on geriatrics.

The Center receives funding support from the National Institutes of Health, foundations and other sources. The Aging Center includes a core faculty of more than thirty, and 96 total faculty throughout the University. It coordinates activities of the Veterans Administration Geriatric Research, Education and Clinical Center, and the Duke Geriatric Education Center, and was recently awarded a Claude Pepper Geriatric Research Training Center grant.

The Center is clearly recognized as one of the "Centers of Excellence" in geriatrics and gerontology in the country. The mission of the Center which is directed by Harvey Jay Cohen, M.D., who is also Chief of the Geriatrics Division at Duke, continues to be to provide multidisciplinary research, education and service activities in gerontology and geriatrics.

I am obviously very proud the work being done at Duke. It is an asset in North Carolina that is shared with the entire country. Research now being conducted at Duke may well provide the key that unlocks the door to understanding Alzheimer's that now creates a major need for respite care to provide relief to so many families today.

Senator Bradley, I appreciate your special interest in respite care and want to thank you for initiating this hearing today. With the growing need for affordable respite care, this is certainly a timely hearing.

Senator BRADLEY. Let's begin with our first panel which consists of Mary Barnette of Monticello, AR, Mr. and Mrs. Louis Spadaro of Toms River, NJ, and from California, Samuel and Mollie Kaplan.

As you are making your way to the table, let me simply express what I know is the feeling of all those in this room who have come to respect, and yet regard with a great deal of affection, the chairman of this committee, Senator Pryor. We wish him a speedy recovery and we look forward to him returning to this chair in very rapid order. So if he is listening, let him know, he is here with us today.

Samuel and Mollie Kaplan, the floor is yours. Take the time you need to tell us the story.

Mr. KAPLAN. Thank you.

Senator BRADLEY. Let me express to all of you, my appreciation for your willingness to share your own personal stories with us. We hope that it will help thousands of people.

**STATEMENT OF SAMUEL KAPLAN OF CALIFORNIA  
ACCOMPANIED BY HIS WIFE MOLLIE KAPLAN**

Mr. KAPLAN. Thank you. Mr. Chairman, distinguished members of this committee, and honored guests, I am Samuel Kaplan of the County of Los Angeles, CA. With me today is my wife of over 40 years, Mollie Kaplan.

All my life I have been a producing member of this society. I grew up and lived my life believing in the American dream, the dream that told me that my country would provide the best care for me and my family. I fought for this country in World War II because I believed that this country needed people willing to take a stand and fight for what they believed in. That's my purpose in speaking to you, today.

When Mollie was first diagnosed at the age of 59 with a form of dementia, in 1986, we naturally sought the second opinions and information to help us make the critical life choices everyone must make. We sought the help of a variety of doctors, but in the passing months we came to realize that no member of this country's medical profession had the answers to all our questions.

Through my employer's health plan I sought help from the HMO that I am a member of. They suggested a geriatric center in the Los Angeles area that specialized in problems like ours. They ran more tests, asked more questions and in time came to the conclusion: "Mr. Kaplan, sorry, we believe your wife has Alzheimer's disease," was all their words came to.

Fortunately, we learned about the Alzheimer's Association chapter in Los Angeles headed up by Peter Braun. They have been so important to Mollie and me. They introduced me to the Valley Senior Service and Resource Center in the San Fernando Valley, where we were offered a 2-day-per-week program of respite care. As their funds were limited, their program was offered for only 10 hours per week. With help only 5 hours per day on Wednesday and Friday, I was forced to retire from my job.

Mollie was no longer able to take care of herself as she had for her entire adult life. She couldn't drive to the market because she couldn't remember where the market was, or how to safely drive her car. Other ailments of advancing age meant she couldn't walk the few miles to the market either. She wouldn't have remembered the way, even if she could have physically made the walk. I was needed at home on a full-time basis just to try to manage the activities of daily life. In fact, I was needed at home to be a parent to my wife.

We all know what being a parent means. Being a single parent of a grown adult means having to do all the cooking and cleaning, the marketing, the laundry, the caring, the loving, and consoling that two parents of a child would normally do. What makes my role different is having to be constantly aware of things. We have special adult-proof locks on the doors to keep Mollie from wander-

ing off while I try to sleep. These same locks keep Mollie a prisoner in her own home.

There have been times when Mollie has forgotten the names of her grandchildren. My grandson, Ken, asked Mollie, "Grandma, do you still remember my name?" Ken was only 6 years old when this occurred. My heart ached when I heard that. This disease is affecting every member of my family.

Mr. Chairman, a few days ago I received a letter from my 12-year-old granddaughter. I'd like to read it to you because it shows how this disease affects our whole family.

DEAR SENATORS: My grandpa asked me to write down what I feel about spending time with my grandma and him. He said you would listen to what I had to say.

When I spent the weekend with my grandparents, it was like being with my grandpa and a child, not the two grandparents I remember from years ago, or even weeks ago. It's strange being around Grandma because you never know what will happen next. She's like a child and you have to be the adult, whether you want to or not.

It hurts because she is always getting worse and when you finally accept how she is, she has changed. And what's even worse, there's nothing I can do about it. It's sad, but I love my Grandma and I'll try to do as much as I can to help her.

Sincerely,

Jenny Kaplan.

The only relief I have is the day care center 2 days per week and visits from my children and grandchildren. Mr. Chairman, members of this committee, I need your help. I am getting too tired to do this daily job by myself.

You provide for rest periods for American workers, limit their daily hours and see that the companies that employ them treat them with human respect. I am just asking that you do the same for me. Can you do something to provide me with a lunch hour, a 10-minute rest break, or the ability to just be alone for a few minutes to enjoy a book or a movie. My job is a 24 hours a day, 7 days a week one. Words and promises are no longer enough for me or the thousands of caregivers like me. We need your support now.

Senator Bradley, we are so pleased that you are introducing the Family Care Givers Support Act. Your bill will be a tremendous help to people like me. Thank you. The Alzheimer's Association will do everything possible to help you get this bill signed into law.

Mr. Chairman, the Alzheimer's Association has written an excellent report on respite care called "Time Out: The Case for National Family Care Giving Support Policy." This report explains the need for respite and the good it can do for caregivers. I would like to ask that this report be included in the record of this hearing and that each of you take a few minutes to read it.

Also, I would like to invite this committee to visit a day care center, to view for themselves the fine work being done everyday for the hundreds of Alzheimer's disease patients. Ladies and gentlemen, see for yourselves what can be accomplished with a handful of dedicated volunteers, a small staff and the space to make it all happen.

Just as in 1944, I have faith in the U.S. Government to do the best for the most people. I never forgot those who have never forgotten this country.

Thank you.

[The prepared statement of Samuel Kaplan follows:]

## PREPARED STATEMENT OF SAMUEL KAPLAN

Mr. Chairman, distinguished members of this committee and honored guests. I am Samuel Kaplan of the County of Los Angeles, California. With me today is my wife of over 40 years, Mollie Kaplan.

All my life, I have been a producing member of this society. I grew up and lived my life believing in the American Dream. The dream that told me my country would provide the best care for me and my family.

Mollie and I raised two children; each living their own lives. They grew up to be fine producing members of society, just like we had intended them to. Each is trying to do the best job for their own families, raising their children the best way they possibly can.

I fought for this country in World War II because I believed this country needed people willing to take a stand and fight for what they believed in. That's my purpose in speaking to you today.

When Mollie was first diagnosed at the age of 59 with a form of dementia in 1986, we naturally sought the second opinions and information to help us make the critical life-choices everyone must make. We sought the help of a variety of doctors, but in the passing months, came to realize that no member of this country's medical profession had the answers to all of our questions.

Through my employer's health plan, I sought help from the HMO that I am a member of. They performed a variety of medical exams, and a battery of psychological tests; coming to the final diagnosis, Mollie had Alzheimer's disease. Now we had a name for the problem, but we still had many questions. The HMO didn't have the answers to any of them. They suggested a geriatric center in Los Angeles that specialized in problems like ours. They ran more tests, asked more questions, and in time, came to the same conclusion. "Mr. Kaplan, sorry, we believe your wife has Alzheimer's disease," was all their words came to.

Fortunately, we learned about the Alzheimer's Association chapter in Los Angeles headed up by Peter Braun. They have been so important to Mollie and me. They introduced me to the Valley Senior Service and Resource Center in the San Fernando Valley where we were offered a 2-day-per-week program of respite care. As their funds were limited, their program was offered for only 10 hours per week.

With help only 5 hours per day on Wednesday and Friday, I was forced to retire from my job. Mollie was no longer able to take care of herself as she had for her entire adult life. She couldn't drive to the market, because she couldn't remember where the market was, or how to safely drive her car. Other ailments of advancing age meant she couldn't walk the few miles to the market, either. She wouldn't have remembered the way, even if she could have physically made the walk. I was needed at home on a full-time basis, just to try to manage the activities of daily life. In fact, I was needed at home to be a parent to my wife.

We all know what being a parent means. Being a single-parent of a grown adult means having to do all the cooking and cleaning, the marketing and the laundry, the caring, the loving and the consoling that the two parents of a child would normally do. What makes my role different is having to be constantly aware of items that two normal parents would never have to worry about. Things like having special "adult-proof" locks on the doors. Locks that will keep Mollie from wandering off while I try to sleep. Yet those same locks keep Mollie a prisoner in her own home.

All of us in this room have a basic understanding of Alzheimer's disease, but it's only the caregivers that truly understand what the daily routine of caring for a fully-grown adolescent is really like. Mollie's mental age has been steadily decreasing over the past few months, and every day brings the realization that another piece of information has been lost to her forever. Up until recently, Mollie prepared our evening meal. Then she started to forget whether or not she had put salt in the pot. This was frustrating to her and it was only with great effort that I was able to ease her mind without losing my own. Now, she, doesn't remember how to cook at all. I prepare all our meals.

There have been times when Mollie has forgotten the names of her grandchildren. My grandson Ken asked Mollie, "Grandma, do you still remember my name?" Ken was only 6 years old when this occurred. My heart ached when I heard that. This disease is affecting every member of my family.

The only relief I have is the day care center, 2 days per week, and the visits from my children and grandchildren. Mr. Chairman, members of this committee; I need your help. I'm getting too tired to do this daily job by myself. You provide for rest periods for American workers, limit their daily hours, and see that the companies that employ them treat them with human respect. I'm just asking that you do the same for me.

Can you do something to provide me with a lunch hour, a 10-minute rest break, or the ability to just be alone for a few minutes to enjoy a book or a movie. My job is a 24-hour-a-day, 7-day-a-week one.

I was asked to come to Washington to tell you what I needed to make my job as a caregiver easier for me to do. What I need, what every caregiver needs, is more respite care, both in the home and in day care centers, and more active support for those people like me doing this job out of the love they've shared over a lifetime with the member of their family stricken by this disease.

Words and promises are no longer enough for me, or the thousands of caregivers like me. We need your support, now. We need the day care centers that will provide a dignified and active place for Mollie, and the thousands like her, to go for activities keyed to her limitations. We need the financial support in the places it will do the most good for the most families; not for a brief time, but for the many years that can be the life-span of an Alzheimer's patient.

I am unable to give any more than I'm doing already. Mollie is on disability, I'm collecting Social Security, and we have two small union pensions. This is barely enough to meet our daily needs. I can't build a day care center by myself. What I can do, and what Mollie and I are doing, is giving of our time and energy to be heard wherever and whenever we can. We only hope and pray that someone, perhaps this committee, can respond to our plight.

Mr. Chairman, the Alzheimer's Association has written an excellent report on respite care called *Time Out! The Case for a National Family Caregiver Support Policy*. This report explains the need for respite and the good it can do for us caregivers. I would like to ask that this report be included in the record of this hearing and that each of you take a few moments to read it.

Also, I would like to invite this committee to visit a day care center, to view for themselves the fine work being done everyday for hundreds of Alzheimer's disease patients. Ladies and gentlemen, see for yourselves what can be accomplished with a handful of dedicated volunteers, a small staff, and the space to make it all happen.

Just as in 1944, I have faith in the United States Government to do the best for the most people, and never forget those that have never forgotten this country. Thank you for your time today.

Senator BRADLEY. Mr. Kaplan, Thank you very much for your testimony and sharing with us those very painful realities.

Mrs. Spadaro.

**STATEMENT OF COLLETTE SPADARO OF NEW JERSEY,  
ACCOMPANIED BY HER HUSBAND LOUIS SPADARO**

Mrs. SPADARO. Good afternoon Senator Bradley, ladies and gentlemen. We are the Spadaros, Louis and Collette, from Toms River, NJ. We have been blessed with six children, of which two are still at home, along with two grandsons.

Our youngest son Thomas, who is here with us today, was accidentally shot by a schoolmate when he was 11 years old. This accident left Thomas paralyzed from the neck down. About 5 years ago, my mother who is 87 years of age, came to live with us. At that time she was able to fend for herself. Unfortunately, 8 months ago she collapsed and since then she has been unable to walk, move about, or attend to her personal needs without assistance.

You can imagine what this episode did to an already busy household. We were now faced with the unpleasant possibility of placing Momma in a home. It then occurred to us to see if there was an alternate solution. As our son was receiving personal services from various Federal and State programs, we decided to inquire as to whether we could get assistance for Momma, with the goal of keeping her at home with us. Fortunately, the Ocean County Social Service Department referred us to the respite program.

After filling out an application, we were advised that Momma would qualify. However, there was a waiting list and they could not give us a definite date of when help would be available.

We then resolved to try to meet Momma's needs by ourselves and hope that the waiting period would not be too long. The pressure of the situation began to tell; we came to the realization that we could not provide the care Momma needed and still have a normal household.

At about this time we were informed that there was an opening and we were assigned a caseworker. She proceeded to arrange a schedule, consulting us so that we could cover Momma's needs with the least interruption of family routine. The respite program has many benefits, obvious and not so obvious. Naturally, the recipient remains at home and the family atmosphere contributes to her well being, but more important, she maintains her dignity. We hope to have an opportunity to explain the not-so-obvious benefits as the hearing progresses.

Senator BRADLEY. Thank you very much Mrs. Spadaro.  
Mrs. Barnette, welcome to the committee.

#### STATEMENT OF MARY BARNETTE OF MONTICELLO, AR

Mrs. BARNETTE. I'd like to thank all of you for allowing me to come here today to speak with you. My name is Mary Barnette. I am here, not only as a parent of handicapped children, but to represent parents of all over of handicapped children.

First I'd like to tell you a little bit about myself. My husband and I are parents of five natural children, the youngest of which was born with handicaps. We have been foster parents for 16 years and in that length of time, we have had 103 foster children. I would say 90 percent of these were—

Senator BRADLEY. Did you say 103 foster children?

Mrs. BARNETTE. Yes sir. They were handicapped children or children with handicaps. Right at this time we're not foster parents. We started to adopt children, so we have six adopted handicapped children now, so we're not still fostering children. We love it, it's great.

I know some of you might think, "Well, this lady chose this life, it's not like she just had a child that was born with handicaps." And that's true, but I think being a foster parent of special children and adopting special children gave me a real insight on the problems that families with these children have.

The thing I want to talk about today is family support. A big piece of this family support is the respite care that we so desperately need. Every child, regardless of disability, has the right to a family and a home. Not all families, like mine, are strong extended families. While I have help from different members of my family, not everyone is blessed with that.

I've found that most families would like to keep their children at home if they had the help and the resources to do it. In a lot of areas the support systems are too few or nonexistent. I live in a rural area and we're just now beginning to get some respite care, that is, it's fixing to come on. We're proud of it though.



What we see so much of with the families that don't have the resources and the help, is that the families start falling apart because it's just too much to cope with the constant demands on you, taking care of the child with handicaps, if you don't have help.

I know in some cases, the families are not even able to go to church together as a family, due to the severe disabilities of the children. Now, a lot of the children are able to go, but there are a lot of children that have severe medical disabilities that don't allow them to be able to go to places like this.

There are a lot of places that the families can't go on vacation because they are not wheelchair accessible. You can't just say, "We're going to the mountains hiking," because how are you going to take a child in a wheelchair hiking? This is really unfair to the child with disabilities. It's also really unfair to the rest of the family, especially to the siblings of these children, when the parents are unable to do things with them.

We see a lot of marriages break apart due to the lack of time that parents are able to spend together. There are many families where the parents must sleep in shifts because their child requires 24-hour care. This is going on in a lot of homes, right at this time.

The other children in the family sometimes suffer because the special child requires so much of the parent's time. This is not always physical care neglect to the siblings, but parents are just not able to give the time to the children that they need, because they spend so much time with their special child.

For example, a normal family had a daughter that was born with severe disabilities and they also had two little boys that were without disabilities. The special child demanded so much of the mom's time that she did not have the energy or the time left to deal with her other two children. While this is going on, dad's working two jobs to try to meet the medical expense and to do all the other things that mom doesn't have time to do.

What happened in this family is that the oldest boy got into the wrong crowd, started drinking and he's now serving time in jail. The youngest boy is now in a drug treatment program. Now, I'm not saying that if they would have had support, that this wouldn't have happened. However, it's a pretty good possibility that if they would have had the support that they needed, this might not have happened.

Families need support that meets their individual needs. Most parents want to keep their children with special needs at home, if they could only get the support that they need. In addition, the support services that help to keep families together and thereby promote healthy families, are much more cost effective than having to place the children outside of the home.

When you have a handicapped child, it's a constant fight to get the services that you need. At the same time you're fighting, you're also the child's primary caregiver, you're trying to be a good spouse, and a good parent while you're carrying on all these other jobs. Parents need respite care to just be able to get away from all of it, at times.

Sometimes what we see happen is that parents begin to get burn-out. Some of you may be familiar with that word, but what hap-

pens is that if its really bad, the child could have to be placed out of the home, and that's not good.

We need trained respite caregivers for our children, not only trained by providers, but trained by the parents about the needs of their individual children. Parents know their child better than anyone.

We need flexible respite care. Sometimes it's provided at only set times, yet families might need respite care at any given time. This includes, but is not limited to emergency respite care, because there is no way of knowing when a sickness or death in the family, or other emergency, might take you away from your family. For example, 3 weeks ago I was hospitalized and needed respite care at that time but there was no plan for respite care.

We need in-home respite care. It is so much easier for the child, the other children in the family, and the parents, to have the respite care in their home. The child feels better in familiar surroundings with their own toys, and their own belongings, and with their other siblings present. It's a lot easier for the parents to be able to leave their children for a few days knowing that their child is going to be happy.

Families need support to keep their children with disabilities at home and to keep the families together. This is why respite care is so important.

Thank you.

Senator BRADLEY. Thank you very much, Mrs. Barnette for sharing your story with us. We will limit questions to 5 minutes per Senator in the order of arrival. That will be Senator Kohl, Pressler, Durenberger, Sanford, and Grassley, in that order.

Let me begin by asking you, Mr. Kaplan, what kind of supplemental respite assistance would be most helpful to you? Mrs. Barnette talked about the variety of types, what would be the most helpful thing that could be available to you.

Mr. KAPLAN. Just to have another face to talk to. Comes the evening, that's the worst time because you're alone and your spouse is asleep. How many hours a night can you watch television? You're afraid to go to sleep because you don't know what might happen. When you finally do go to sleep, it's sheer exhaustion that puts you to sleep. I can't recall when I have had a good night's sleep. I take a look at my wife laying next to me and I can feel her breathing and hear her breathing. I put my arm around her and in no time at all, it's a breathing of relief. She's relieved, she knows somebody is there. How can you put into words what a person needs? It's very difficult, Mr. Chairman.

Senator BRADLEY. What do you do when your wife is at an adult day care center?

Mr. KAPLAN. I drop my wife off at 10 o'clock in the morning. I go over and see a friend of mine who lives in a retirement home, maybe we go out to lunch. I take a look at the clock. It's 1 o'clock. By 1:30, I'm back at the day care center. I've got to pick up my wife at 3. I'm there at 1:30. How can I—I feel guilty after 45 years of marriage, for being away.

We have some volunteers coming into the program, a pianist and his wife, Eleanor. They do some singing for us. So, I walk in at about 2:30 in the afternoon, pick up my wife Mollie and we have a

few dances together. I go around introducing myself to all the patients. I thank all the volunteers for their efforts. I tell them, "Please, do me a favor, go home and have a good shot on me, you need it." [Laughter.]

Senator BRADLEY. Thank you.

Mr. KAPLAN. You're welcome.

Senator BRADLEY. Mrs. Spadaro, what kind of services do you use?

Mrs. SPADARO. We have a home health aide coming into the house to help take care of my mother, and thank God for it, because I am a working mother, now at this present time. Without them coming into the home, I wouldn't have peace of mind to go out the door and leave my mother alone.

Senator BRADLEY. How often do they come in?

Mrs. SPADARO. I have one in the afternoon for 2 hours and then I have somebody else or the same person, for 2 hours at night.

Senator BRADLEY. And what does that allow you to do that you couldn't otherwise do?

Mrs. SPADARO. Well, the fact that I am working—working mainly because 2 years ago my husband was locked out of his job, which kind of forced me back into the work force. I was able to get benefits to cover myself, my husband and my handicapped son Thomas.

Senator BRADLEY. So, it allows you to be the breadwinner and keep your benefits in terms of pension and health.

Mrs. SPADARO. Exactly, exactly.

Senator BRADLEY. If it wasn't for respite care?

Mrs. SPADARO. I would not be able to do it, it's impossible.

Senator BRADLEY. Well, what would happen?

Mrs. SPADARO. Well, I would have to stay at home. I would have no choice. My mother is in the position where she cannot do anything alone, whatever she does, she needs assistance. She needs assistance from the time she's out of bed, she needs assistance getting out of bed, she needs assistance getting into bed and throughout the rest of the day. This means, maybe in the course of the day I might have 2 or 3 hours where I can do other things, other than caring for my mother, which is not enough time to hold down a full-time job, naturally.

Senator BRADLEY. My time is up, Senator Pressler.

Senator PRESSLER. Thank you. To follow up a little bit on some of this, I might ask Mary Barnette, who's story I found very moving, what sort of training is it necessary to have for somebody to be involved in respite care? Can anybody do it and what kind of training should they have?

Mrs. BARNETTE. Well, it would be according to the individual. A lot of the children have tracheotomies. I don't know about everyone else, but I wouldn't leave a tracheotomy child with someone that had not had tracheotomy training. I think it has to do with the individual child and their medical disabilities.

Senator PRESSLER. How can you be sure if someone is trained properly in this area?

Mrs. BARNETTE. Before I leave my child with someone, I want to see them work with my child and know that they know what they're doing.

Senator PRESSLER. Mr. Kaplan, how could respite care programs better meet the special needs of caregivers who care for a family with Alzheimer's disease? There again, I know Alzheimer's disease has various stages, but would you rather see an expansion of in-home respite care services or out-of-home services?

Mr. KAPLAN. At the time being, I go for the out-of-home services, considering the state this Alzheimer's disease has progressed to. We do not need in-home service yet, thank God.

As for out-of-home service, it would definitely be needed. They would give the caregiver some added time to get accustomed to being by himself, to do the chores, take care of the responsibilities of parenthood, take care of the home and just to fulfill his responsibilities.

Senator PRESSLER. Good, I have some additional potential questions for the record. I have to leave to go to another meeting. I look forward to hearing Mrs. Sarnoff, I shall read her statement and I thank her very much for her presence.

Senator BRADLEY. Senator Durenberger.

#### OPENING STATEMENT OF SENATOR DAVE DURENBERGER

Senator DURENBERGER. Mr. Chairman, let me begin by thanking you for having this hearing and remind people in the audience that for the 12 or 13 years that I have served with you on the Senate Finance Committee, you've been talking about this subject, not only on the Finance Committee, but in budget reconciliations at the end of the year. Any time there's a Medicare bill up, you're talking about it. Anytime there's a reform of Social Security, you're doing the same thing. So, I complement you for your persistence.

Are we down to 2 minutes? Is that the way it works?

Senator BRADLEY. No, after that comment, I'm sure this light is not working properly. [Laughter.]

Senator DURENBERGER. I think all of us, especially those of us like Bill and I, Chuck Grassley, and others who have been on the Finance Committee, have spent a fair amount of time dealing with the Social Security Act and how it can more realistically provide access to long-term health and medical care. We've been in some of the States of our other colleagues. I've been in South Dakota with Larry over the years visiting with people who would like not to be institutionalized but are institutionalized only because there is not an affordable family setting. There's family, but there's not an affordable family setting, because of either the costs involved or the medical necessities. So, a lot of us have a variety of experiences. We have it with some chronic illnesses and we have it with some of these long-term illnesses like Alzheimer's and Parkinson's and so forth.

Out of the Finance Committee began this Alzheimer's demonstration—and there's a couple of people from the project that we have going in Minnesota that are sitting back here posing as staff to the Senate Aging Committee. We've been working hard at trying to figure out how we can best use the social insurance system to supplement people's earnings and various other resources.

One of the problems we keep running into is that when the government is spending somebody else's money, how do you account for it? That's why the first question you got, Mr. Kaplan, was about what your needs are. That actually gets translated into kinds of services. Then somebody says, "Well, in order for a person to give you those kinds of services, they have to have these kinds of qualifications." And then somebody has to fill out the forms, you know, and all that sort of thing. That seems to be one of the discouraging things about trying to legislate relatively small amounts of financial support for alternative systems outside the home, like in respite care, or systems inside the home like homemaker and some of these other things.

So, if anyone of you have had a particularly good experience with a community-based system, where there was a manager or a person who was responsible for helping you make decisions about what kind of medical care you should have come into the home, or that now is the time to seek this kind of service here or there—has anybody had an experience in your community with one person to whom you could go and describe the condition of a spouse or a child, and they say, "Now is the time to get this person to come in," or "Now is the time for you to go here," and kind of help you manage this process? Mr. Spadaro, did you have that?

Mr. SPADARO. Yes, Senator. In Ocean County we have an enlightened program, as my wife mentioned to you. When the woman came in—first off she was a registered nurse, so she was familiar with the medical problems that my mother-in-law had. She also sat down with us and had us explain our routine. My mother-in-law doesn't have Alzheimer's disease, she has all her mental faculties and she probably knows you guys by name if she sees you on TV. This woman and this program was very good, in the fact that she had this—we get 6 days a week and she arranged the hours to fit my wife's routine. At the present time, I'm a seaman. I work on a seagoing tug and I work a 2-week cycle, 14 days on and 14 days off. I haven't been out of work for the 3 years that Collette mentioned. I just didn't have a job where they gave me benefits. I was a temporary employee that worked permanent.

Another thing, these programs are very good. I point to my son, Thomas, who has been disabled now for 13 years. Tom is going to receive his bachelor's degree in September. Tom is on the board of directors of a crippled children's camp. Tom, last year, was capable of going to Florida for the spring break with his buddies.

The respite care allowed us to go away on a ski weekend. They came in and they took care of Mom for the 2 days. We all went up to the State of New York and went skiing. Tom skis with what looks like a stoke stretcher, they tie him up and send him down the hill. [Laughter.]

It scares the crap out of me, you know, I can't watch it.

But in any case, these are some of the things—we've had very good experiences. Through the years we've been able to use different programs to Tommy's benefit, to the society's benefit and to ours. I don't know if I make myself clear.

Senator DURENBERGER. Right, great, that's a big help, that's a big help. Thank you very much.

Senator BRADLEY. Thank you very much. Let me, if I could, just ask one or two other questions of this panel and then we want to move to our next panel.

As we think about what to do that could be the most helpful in your circumstances, I hear you saying a couple of things. One thing you're saying is that you'd like to have the flexibility to be able to choose among a number of possible services: adult day care in Mr. Kaplan's case, homemaker aid, someone to come in, in the afternoons in the Spadaro's case, and in Mrs. Barnette's case, maybe a chance to get away or some chance to recognize that handling children with disabilities is stressful and a little break from that, even though you choose to handle disabled children.

Mrs. BARNETTE. Right.

Senator BRADLEY. One of the thoughts is that your situation requires a range of services. Would each of you agree to that Mr. Kaplan?

Mr. KAPLAN. Yes.

Senator BRADLEY. Mrs. Spadaro?

Mrs. SPADARO. Yes.

Senator BRADLEY. Let the record show that everyone is nodding their head. In terms of amount, could each of you use respite services if more were available?

Mrs. SPADARO. Yes.

Senator BRADLEY. What additional requests would you say could be met in your case, Mrs. Spadaro?

Mrs. SPADARO. The way I see the program now, there is a certain amount of time allotted to respite care to relieve the family of the responsibilities of say, my mom. As far as I know, it's 14 days per year. Now, that's great. I'm not knocking it in any way, shape, or form. So far we've used it a couple of times. I find myself very cagey, making sure that I plan well before using it, because it is going to run out. There, we would like a little more flexibility, more time allotted, because that one weekend that we were able to go away meant so much to my entire family. Also, knowing that my mother was well taken care of, it took all that pressure off me. It's just like a big sigh of relief to be able to walk out that door knowing that mom is going to be taken care of, and we are going on a "normal vacation."

Senator BRADLEY. Mrs. Barnette, you say that there has just begun a respite program—

Mrs. BARNETTE. Yes, there is.

Senator BRADLEY. So you obviously would seek to expand it in a variety of ways.

Mrs. BARNETTE. Yes, sir. We have just completed the paperwork.

Senator BRADLEY. Pardon?

Mrs. BARNETTE. We've just completed the paperwork on the Medicaid waiver for our family. I think it is going to work out for right now, anyway. It's going to be better than what we had, which was nothing.

Senator BRADLEY. So, if we agree that there should be a range of services offered and that it should be in an amount that is helpful, as opposed to simply a token, is there another principle that we should agree to, that there should be some income level where it should not be available. Someone who makes a \$1 million a year

shouldn't dip into that pool that people who are making \$25 thousand, or \$10 thousand, or \$40 thousand a year, dip into. Does that make sense to you?

[Nods from panel.]

Senator BRADLEY. Let me tell all of you how much I appreciate your willingness to come and share your personal stories. So often it is a reminder to all of that our job is not just to write laws, but to write laws that improve the quality of life for the people that we serve. Your presence here today, describing your own circumstances and how you think respite care legislation could improve your own circumstances, and your family's circumstances, is enormously helpful. I want to thank you very much for taking the time today to come.

Mrs. BARNETTE. Thank you.

Mrs. SPADARO. Thank you.

Mr. KAPLAN. Thank you.

Senator BRADLEY. We'd like to move on to a second panel now. The second panel consists of Miss Lisa Gwyther, Director of Duke Family Support Program, Durham, NC, Mr. William Ditto, Administrator of New Jersey Office of Planning and Special Initiatives, Trenton, NJ, and Mrs. Lolo Sarnoff, President and Founder of Arts for the Aging in Bethesda, MD. Let me welcome all three of you to the committee.

All three of you are professionals. You are the ones who will put the very compelling personal stories that we've just heard into a programmatic context. I am anxious to hear your comments. Let's begin first with Ms. Gwyther.

#### STATEMENT OF LISA GWYTHER, DIRECTOR, DUKE FAMILY SUPPORT PROGRAM, DURHAM, NC

Ms. GWYTHER. Thank you for the opportunity to testify about a topic of immediate concern to American families caring for chronically ill relatives.

My name is Lisa Gwyther. I'm a social worker. I direct the Family Support Program of the Duke University Aging Center. Since 1982 we've studied the impact of caregiving on families of memory impaired older adults, and specifically, the effectiveness of respite services. Our findings mirror those of several national respite research studies. We believe dementia illness may provide a prototype for a model respite policy.

Respite is time out for unpaid family members who provide continuous supervision and care for a relative who can't safely be left alone. Alzheimer's patients require constant, vigilant supervision and cuing. Their gradual loss of initiative, impulse control, and judgment place them at significant health and safety risks. The toll, particularly in caregiver mental health symptoms, loss of privacy, time and energy to meet personal needs, is catastrophic. Respite provides brief, intermittent, dependable, time off. It can be offered in the patient's own home, a group day setting, or overnight in a residential facility. What makes it unique is its potential to preserve family strengths, energy, quality and effectiveness of family care.

Respite offers potential benefits to the entire family system in meeting other valued commitments. Most health programs, eligibility, and benefits, are solely directed at an identified patient. Eligibility, access, equity, and availability barriers, disenfranchise many families caring for chronically ill. Most health services don't address the primary needs for active human supervision, basic personal care, stimulation, and companionship. Respite expands this eligibility and the potential for positive outcomes within a family.

Most respite is provided by secondary family members and friends who mobilize well for brief periods but aren't dependable for the long haul. Respite research documents a variety of positive outcomes. But despite the positive outcomes, knowledge about the service and expressed need, only 25 percent of all Alzheimer's families use any respite and only 2 percent of that is publicly funded.

Most paid help is private. It's used in the final year before death or placement of the patient. Evidence is mounting that the demand for respite is reasonable, controllable, and much less than we professionals recommend. Respite responds to family needs for flexible, high quality, and affordable programs. The response of families has been overwhelmingly positive, regardless of the amount or type of service used. What families appreciate is the opportunity to retain control, to tailor it to the mutual benefit of patient and family, and the convenience of flexible, consistent, affordable, trained help.

Our studies found that the average in-home respite use was 6 to 8 hours a week, although people said they needed 15 to 20. Respite care can't operate without outreach, counseling, transportation, and subsidies. Demonstrations consistently document modest increases in the caregiver's well being and mood, time available for personal needs, support from other relatives and friends, and perceptions of improved effectiveness of family care and coping.

Often a positive first experience with respite leads to appropriate preventive service that minimize or prevent secondary disability in the caregiver, or even family conflict. The long waiting lists for quality respite program services—as the testimonials we heard today indicate, even brief respite might be just enough to sustain family capacity.

Respite is short-term, used from the time families begin to provide continuous supervision until the patient requires skilled terminal care.

Respite policy is a pro-family, gap-filling approach. It addresses family concerns about autonomy, and quality of life, as well as quality of care. It's one of a number of ways to support the family's preferred level of involvement and expressed wishes to act on feelings of love. There is ample evidence that despite the lack of appropriate respite, family heroism and strength is more common than defeat.

Respite is modest and affordable. It's not a panacea or a convenience. It's not an alternative to another system. It's a piece of a potentially rational system.

There is also adequate evidence that respite can be targeted to families at greatest risk of negative outcomes from caregiving, thereby potentially reducing future societal costs.



Chronic illness is an equal opportunity problem. At some point in time, 15 percent of our families will have a relative who requires constant supervision and care. Although it is not crisis intervention, respite can buffer, minimize or delay, some emotional, health, and economic, family crises. Respite is also is not for everyone. It can't serve persons who have outlived available family support or persons who can safely stay alone. It can't be expected to encourage an unwilling family to provide care, or discourage a willing family from being involved. It is not high-tech. It is high-touch and labor intensive.

Respite care is not necessarily cheaper because its costs are currently borne out-of-pocket.

Respite policy offers an opportunity for a creative alliance between families, government, professionals and voluntary associations, to help keep the family in the driver's seat.

We must be realistic in outcome expectations from modest programs. Six hours a week for the family of an Alzheimer's patient isn't going to make the patient better or eliminate family stress. It is an innovative opportunity to meet universal family needs and wishes in a dignified and limited way. The attractiveness rests on the recognition of family contributions and preferences to remain in control.

Moral, equity and access arguments for respite are far stronger than economic ones, based on reducing the negative consequences of chronic illness on family well being, family care effectiveness, providing all gap-filling services, accepting families as worthy beneficiaries of prevention oriented services, and achieving greater equity in quality, between and among, home and institutional services.

Thank you.

Senator BRADLEY. Thank you very much, Ms. Gwyther.  
[The prepared statement of Ms. Gwyther follows:]

PREPARED STATEMENT OF LISA P. GWYTHYER

Mr. Chairman: Thank you for the privilege and the opportunity to testify at this special hearing of immediate concern to the growing number of American families caring for chronically ill family members. My name is Lisa Gwyther, and I am a social worker. I direct the Family Support Program of the Duke University Center for Aging. The Family Support Program is a state central information, referral and technical assistance program for families of chronically ill older persons. Since 1982, we have conducted studies of Alzheimer's family caregiving and the effectiveness of respite services in particular. My comments today will summarize not only research at Duke, but evidence from large national demonstrations and the few rigorously controlled studies of respite outcomes. Although my experience and research is limited to families of adults with memory-impairments, our findings mirror those of several major surveys of family caregivers of impaired older persons. Indeed, the effects of Alzheimer's and related disorders on patients and their families may serve as the prototype for a model respite care policy.

Our present "system" of long term care is essentially an underground of informal unpaid family care. There is ample evidence that families will continue to assume emotional responsibility, regardless of distance or commitment. There is also ample evidence from 20 years of research that formal paid services will never substitute or discourage family involvement. The majority of formal long term care services are used by the 20 percent of memory-impaired elders who have outlived available kin. Most families care for their own based on values, notions of family solidarity or a lack of available alternatives.

Research consistently indicates that the demands of caregiving can and often do generate demonstrable negative effects on families. For example, Duke studies com-

pared Alzheimer's caregivers to age-matched community peers and documented substantial decrements in mental health, quality and quantity of personal time and overall life satisfaction among caregivers. Alzheimer's caregivers reported three times as many psychiatric symptoms and were four times as likely as non-caregivers to use psychiatric medications and alcohol to cope with stressful demands. These outcomes, often defined in terms of emotional, physical, time or financial burdens, are costly unintended consequences of our continued *exclusive* reliance on family care. Secondary disability in caregivers, other unmet family needs and decreased effectiveness of patient care are other significant risks of our "hands off" policy toward family caregivers of persons with chronic or degenerative conditions. Despite this potential for negative outcomes, family heroism, commitment and strength is more common than defeat.

Respite services are a minimalist, first step toward preserving family care strengths and potential. Respite policy is essentially pro-family policy. The policy interest in family care is both social and economic. Chronically ill people and their families prefer to remain in valued familiar settings, and the costs of long term formal care are escalating. A respite policy addresses socially valued priorities with a formal service that is currently available only on an ad hoc, informal basis.

A respite policy would not replace one "system" with a less costly system. Respite policy addresses issues of equity in public vs. private costs. Respite outcomes are modest because the service itself is modest relative to the enormity of the chronic care problem, but respite care may be just enough to sustain a family's preferred level of involvement in offering personalized care in familiar dignified surroundings. Respite is only one piece of long term care, and it is not appropriate nor a panacea for all chronically ill persons and their families. However, in most large scale surveys of family caregivers, respite services are identified as the most needed, yet least accessible or available of all formal long term care services. In essence, respite services partially close the gaps between acute medical and nursing services, residential and terminal skilled care.

How does research define respite care? Definitions vary, but respite, in essence, is time out or time off from the continuous supervision and care associated with unpaid family assistance to a relative who cannot be left alone. Time out may be brief, scheduled, intermittent, or as needed and it may be provided by someone coming into the home, at a group day center, or overnight in one's own home, a residential or institutional facility. What makes respite unique is the potential benefits to the patient, family caregiver and the entire family system in meeting other obligations and commitments. Eligibility for most health and social services or entitlements is limited to the characteristics of the identified "patient." Respite services expand potential eligibility and positive outcomes for multiple persons within a family.

Respite is not a procedure—chronically ill persons vary in their functional needs for assistance and the timing and dosing of time off and what is done with and for the family should fit the needs and wishes of patient and family. Some family caregivers may need the time to sleep, run errands, or spend time with other family members or friends. Some must use limited time off to conduct family business or keep up valued connections to other potential sources of support.

There are many things respite cannot provide. It cannot provide full-time substitute care. It is not a service for impaired persons who have no unpaid family caregivers. It is not a service for impaired persons who can safely stay alone.

If respite care is so intuitively appealing, why are hearings like this necessary? First, over 80 percent of respite care is currently provided informally by other family members, friends and neighbors who are first-line preferred sources of relief for most family caregivers. These unpaid secondary caregivers can generally mobilize for short term crises or relief, but sustained consistent assistance from other relatives and friends is not available over the long haul. Second, family caregivers don't understand terms like "respite." A man with a sick wife views himself primarily as a husband or professional, and may view his wife's care as just "doing what she would do for me if circumstances were reversed." If his daughter takes care of her mother when her father is away, she wouldn't see herself as a respite worker any more than he sees himself as a caregiver.

If families of chronically ill don't know what respite means or don't define themselves as caregivers, what do they want? Many families describe needed help in generalist terms—"someone to come in a couple times a week to help my wife with personal care or a meal and provide some companionship." The focus of these frequently altruistic family caregivers is on what happens to the patient even though they may need the time off as much as the patient needs supervision. Some families ask if there are places an impaired elder can go for structured, failure-free social stimu-

lation and the chance to meet new friends. Others ask if someone could "just keep momma while daddy is hospitalized or recovering from illness."

Memory-impairments pose special problems in finding relief or time out. The patient may not be aware of his disability, and may react with anger, suspiciousness or hostile retaliation to respite workers or to their relatives for presumed betrayal. Alzheimer's patients' behavior may be unpredictable and their families are forced to be hypervigilant, thinking and planning ahead to avert health and safety risks posed by the patient's poor judgement. This constant state of vigilance takes its toll on caregivers of any age, and many families are embarrassed or threatened by what the patient may do in the presence of a paid helper. Alzheimer's patients need supervision and cueing with basic personal care tasks. They are frightened people who need repeated reassurance in the face of losses and assaults on their self esteem. Families find it difficult to remain patient and reassuring when they have repeated answers to the same question all day or searched in vain for misplaced valued items "hidden" by their suspicious confused relatives.

What families need and what they want may be very different. At a minimum, family caregivers need personal time. Alzheimer's, in particular, has been shown to increase the risk of mental health problems associated with lack of privacy and social isolation. Although not all outcomes of family care are negative, the risk of secondary disability in caregivers and consequent reduced effectiveness of family care are very real.

What families want is as varied as the families affected by chronic illness care. In general, they want to remain in control, they want high quality, knowledgeable, experienced sensitive helpers. They want respite when the patient and family can best use the limited time apart. They want pro-active care, not custodial holding actions. They want something that will enhance the effectiveness and quality of family based care at a bearable cost.

From a policy standpoint, the issues are ones of equity, access and quality. To preserve valued family strengths and valued personalized quality care, costs could be more equitably shared between government, voluntary organizations and families. Medicaid pays 44 percent of the national nursing home bill, but no public source pays anywhere near that share for respite services. Families of Alzheimer's patients are reluctant to spend anything on respite given realistic fears of future looming out-of-pocket costs associated with terminal nursing home care. As a nation, we should be as concerned with the quality of family care as we have most recently concerned ourselves with reforms addressing the quality of nursing home care.

Access to respite care is limited by lack of information, confusion about labelling of services, and a genuine limitation of family-centered long term care services. Stronger evidence exists for moral vs. economic arguments for respite care, and an overview of the research will pinpoint why this is inevitable.

Only one quarter of Alzheimer's families use any formal services other than physicians. The minority who do use formal services tend to use them reluctantly, to underuse community services and to delay use of any community service until just before the death or institutionalization of the patient. Families of Alzheimer's patients in particular seem to reach out fleetingly and often before using any service in a last-ditch effort to sustain preferred family care. Often the level of need at this point is beyond the minimal capacity of any limited respite options. Recent evidence from Duke and other studies indicates that most of this respite care is sought and paid for privately, creating a separate underground of unsupervised, untrained and unregulated paid helpers who are not connected to mainstream health and social service agencies. These paid services are under-reported in caregiver survey research because families think such private "maids, sitters or companions don't count." National and regional respite studies consistently report underutilization, delayed utilization and a general reluctance of families to relinquish, however briefly, physical responsibility of a beloved impaired relative. Research further documents that knowledge about services, need for the service and service availability do not readily translate to use. In general, families use many fewer services than professionals would prescribe.

There is no evidence from any major studies that families of chronically ill will crawl out of the woodwork as soon as any new benefit program is available. In fact, the largest single research evaluation of expanded reimbursable respite, the HCFA Alzheimer's Medicare Demonstration, was forced to extend enrollment to get a sufficient sample to test the effectiveness of case management and respite care. In the Duke respite demonstration, 50 percent of the patients were institutionalized or died within 8 months of initiating in-home respite services and 25 percent of these families began respite use only 1 month before death or placement of the patient. There is no reason to assume that families will abuse a respite benefit, nor is there any

hope of documenting significant outcomes from such a brief limited service. Another national day-center based respite demonstration has preliminary evidence that families can and will cover the major costs of innovative high quality respite programs.

There is evidence of modest benefits from appropriately modest services like respite care. The Alzheimer's Association national respite care demonstration and research at the Philadelphia Geriatric Center demonstrated several positive patient and family outcomes, including a small, unanticipated delay in institutional placement. However, it is generally agreed that respite care cannot be expected to delay or prevent more expensive terminal nursing home care for persons with degenerative brain diseases. Respite is useful for a brief time in a degenerative illness between the time an impaired person can be left alone and the time full time skilled nursing care is needed. To expect respite care to substitute for more expensive skilled nursing care is like comparing apples and oranges.

Duke studies of respite care demonstrated modest benefits in caregiver well-being, increased quantity and quality of personal time, increased positive mood among caregivers and more appropriate timely use of other relevant community services. Duke respite users reported enhanced effectiveness of family care with the availability of the fresh trained approach of an in-home respite provider. Respite users also reported enhanced understanding and support from other relatives and the community. Respite users were more likely to be poor, minority group members who were more stressed and had less dependable family support than previous Duke Alzheimer's caregiver research subjects. This provides some evidence that respite services can be targeted to a particularly vulnerable family caregiver. Duke studies, like most other studies of respite care, found family satisfaction with the service was overwhelmingly positive. As one wife in Duke's respite research program reported, "I just wish I could have more (respite.) As with everything else, it comes down to money. We always paid a lot of taxes, and we had three kids to raise and not much schooling. I just know I could be more patient with Clyde if I had more help. "I don't mean to complain—please don't stop!"

Good respite programs have long waiting lists, consistent, dependable and well-trained providers, and frequent anecdotal reports of positive outcomes. Most Alzheimer's families don't expect or want charity programs because they value retained control and choices in how help will be offered. There is no evidence of abuse of respite care programs, but there is consistent evidence that respite programs provide limited, brief but uniquely appreciated and helpful services. For example, the average respite user in the Duke studies used only 6 hours of in-home help a week although they reported "wanting" 15-20 hours per week. There is little research evidence of what constitutes ideal frequency or dosing of respite, but many clinicians believe that measurable cost effectiveness or other significant outcomes are precluded by "insufficient dosing" of the service. It is equally hard to document, other than on a case basis, evidence for prevention of secondary disability in caregivers. Many older spouse caregivers knowingly endanger personal health to fulfill valued commitments to a long term marital partner. Six to 8 hours of time out is unlikely to reverse long term wear and tear on older caregivers although it may significantly improve subjective perceptions of mental health and well being.

Studies consistently document that the objective amount or types of help offered to family caregivers are much less predictive of positive outcomes than the caregiver's subjective perceptions of the adequacy or dependability of that help. It's not how much help is offered that determines caregiver burden. What is most predictive of caregiver well-being is whether or not the caregiver *thinks* her time off or available support is dependable and enough.

Research has yet to document relative merits of different respite settings, providers, frequency, intensity or reimbursement mechanisms. If respite is a unique preventive or supportive service, then there are no comparable formal services to contrast with it in measuring relative cost effectiveness. Until respite is more universally available, it will be hard to predict public and/or private costs. Private costs have been notoriously difficult to document. We do know that demand can't be predicted solely on estimates of the population at risk. We know that knowledge about a type of service and its availability is necessary but not sufficient to encourage demand or use. Acceptability issues and subjective personal, familial or cultural barriers will always preclude use of formal services for some family caregivers. Objective barriers of access and availability for geographically or regionally diverse populations will further limit potential use of respite services.

Respite policy is gap-filling, incremental, pro-family policy that meets the unique short-term needs of patients and families facing long term disability. It is not a panacea or a cheaper alternative, but it is an innovative opportunity to meet universal family needs and wishes in a dignified limited way. The attractiveness of respite

care policies rests on the recognition of family contributions and preferences to remain in control of care and quality of life for chronically ill relatives. Economic arguments for respite based on cost effectiveness are probably flawed for a number of reasons: 1) Most institutionalized patients have outlived available family care. 2) Most institutionalized patients are not prematurely placed based on severity of symptoms or functional impairment. 3) Respite will probably be most attractive to families who may not consider placement unless circumstances force it. 4) Community based care at the intensity often needed is not necessarily cheaper, especially with losses of economy of scale inherent in family care.

More cogent moral arguments for a respite policy are based on reducing negative effects of caregiving on family well-being, enhancing family care effectiveness, providing all gap filling services in the long term care continuum, accepting family caregivers as worthy beneficiaries of prevention-oriented services and achieving greater equity and quality between and among home and institutional services.

Trends toward more single adults, more divorce, smaller families, delayed child-bearing and increased labor force participation of middle aged women all mean future older persons may not have the potential range of currently available family care. Current policy suffers from a lack of funding for most needed personal care and respite services and lack of research evidence about how best to provide timely, effectively dosed respite or support services at a bearable cost. We can't predict demand on needs or dependency projections alone, and we can't test respite outside the context of a full range of vital, necessary long term medical, social and residential services. When that time comes, policy will not only mean well, but do well.

Thank you.

Senator BRADLEY. Mr. Ditto, welcome to the committee.

**STATEMENT OF WILLIAM DITTO, ADMINISTRATOR, NEW JERSEY OFFICE OF PLANNING AND SPECIAL INITIATIVES, TRENTON, NJ**

Mr. DITTO. Thank you very much. Mr. Chairman, members of the committee, good afternoon. I'm William Ditto from the New Jersey Department of Human Services and I'm very pleased to be here today.

I guess I'm "the nuts and bolts" bureaucrat testifying here, who can tell you about our experiences running a statewide respite care program. We've been administering a respite program for the past 3 years in New Jersey. During calendar year 1990 we served about 1,900 families under our program, and we expect to serve somewhere between 2,000 and 2,100 families during 1991. We do this on an annual budget of approximately \$4 million.

We do have a waiting list for this service. Our waiting list is about 500 families at the present time. I believe that by the end of next year we will have reached most of the people on that waiting list and will have been able to offer them some form of service.

Appended to my written testimony is a detailed description of our program so I won't bother to go into that. Just briefly, to let you know what our program's focus is, our target is the unpaid caregiver of a functionally impaired adult over the age of 18, or caring for a frail elderly individual.

Our program includes a menu of services, a variety of services from which families can choose. They include companion, home-maker-home health aide, social and medical adult day care, and out-of-home care in licensed medical facilities.

We have a cost cap of \$2,400 a year per family for the services that we provide. In the event that an unexpected emergency occurs within a family, which requires additional service, we will go up to double the amount of the cap, if necessary.

Our program is operated through county sponsor agencies. Each of our 21 counties in New Jersey has an agency which operates the

program locally, and purchases or directly provides the type of respite services that family's request, following a thorough assessment of the families circumstances, which covers their social, emotional, psychological and financial situation.

I would like to use my time today to address four issues which we believe are crucial based on our experience in operating a state-wide respite program, and which we feel are instructive to other States, the Federal Government and to Congress, as you explore this very important topic.

First of all, we believe very strongly that the degree of the caregiver's stress and burden should be an eligibility factor in respite programs. We have been particularly concerned in New Jersey with family caregivers who are finding it exceedingly difficult to manage their role and who need the support and service that is afforded through our respite program. So rather than relying purely on the functional impairment or level of disability of the person they care for, we are tremendously concerned with the emotional and physical impact of caregiving on the families that we are working with.

Second of all, I want to talk about caregiver education and support. Third, I want to discuss, the need for a "menu of services" or the variety of services available to a family, and finally, I want to stress what we believe is the importance of cost-sharing as both a desirable feature in respite care programs and good public policy.

We believe that it is possible, in measuring caregiver burden, to use various objective scales which can be a critical factor in determining which families to offer respite to in the event of limited resources. As I mentioned to you before, we have a 500-person waiting list and so we have to be concerned about providing our respite services to people who are having the most difficult time coping with their circumstances.

We've had a research project done by the Rutgers University Institute for Health and Health Care Policy and Aging Research, in which they used a scale developed by the Philadelphia Geriatric Center, which was found to be very useful in measuring caregiver burden and stress.

Another important factor and component in respite programs is caregiver education. Many, many people assume the role of caregiving very gradually. They have no training, they have no experience. They start out by doing a few errands or providing a small amount of direct assistance. Then suddenly they're into providing personal care. They're bathing people, they're dressing people, they're feeding people, they're transferring them from bed to chair, all activities which, in the formal caregiving system, we do not allow untrained individuals to perform.

These caregivers are wasting energy. They're risking injury to themselves and to the person they provide care for and they're experiencing increased stress as a result of not being adequately prepared for the role of caregiving. We strongly recommend that programs incorporate in-home consultation services for families which can help them to learn the proper way of providing care.

We further recommend that programs develop caregivers handbooks, as we have done in New Jersey, which has given us the ability to send out a booklet done with simple, straightforward lan-

guage which explains to families how to assist with some of these daily living activities. We're now experimenting with a video tape program that people can view in their own homes if they are lucky enough to have VHS equipment to watch it—which will give them direct instructions.

Another important element is caregiver support. Most caregivers express feelings of isolation, depression—especially those who are spousal caregivers—and feelings of total responsibility for both the health and quality of life of the person that they care for. They need an opportunity to share their concerns, problems and solutions with other people in similar situations.

We have been running groups throughout the State. We have found that these groups are not only providing immediate support to caregivers, but there's an educational component. They're learning more about how to give care. In addition to that, it's providing them with friendships, people to reach out to, people to stay in contact with, who are doing the same sorts of things that they are.

Regarding the menu of services, I am absolutely convinced, after our 3 years of experience, that respite is not a single service. Respite is a strategy. That strategy embraces a number of services and they must be tailored to the needs of the family, individually planned and must be developed in consultation with the caregiver. What is acceptable to one caregiver is unacceptable to another caregiver. We have people who say, "Don't take my loved one out of my home, I will not have them leave this house. I only want a person to come in." Other people say, "The only way I will get relief is if my family member is out of the house for a certain period of time." Those preferences need to be respected and acknowledged.

Plus, people need to make economic decisions. Our services have different price tags. Companion service is our lowest cost, most economical service. The family that wants to get the longest period of service is going to use companion. It means that they're going to have to make sure that the person they care for is set up and ready when the companion comes, because companion is non-hands-on care. By the same token, the use of social or medical day care can be a lot more economical and a lot more reliable than homemaker/home health aide service. We want families to make their own choices.

This past year, we have experimented with providing camp programs, out of home, for younger physically disabled clients. We didn't feel that nursing homes and long-term care facilities were a very appropriate placement for the younger population, such as the Spadaro's son. We want to be able to offer a service which is age appropriate and which is meaningful and beneficial to the care recipient as well as to the caregiver.

Last of all, the area of cost sharing. In our Rutgers study, 53 percent of the families who are not required to share in the cost of care indicated that they would be willing to do so if they were asked to. Cost share money has been easily collected in New Jersey and has been used to meet special needs, to deal with sudden emergencies, to develop specialized services and to assist in furthering the program.

I thank you for the opportunity to testify.

[The prepared statement of Mr. Ditto follows:]

PREPARED STATEMENT OF WILLIAM A.B. DITTO

Mr. Chairman and members of the committee: I am William A.B. Ditto, Administrator of the Office of Planning and Special Initiatives in the Division of Medical Assistance & Health Services at the New Jersey Department of Human Services. My office is responsible for the operation of the Statewide Respite Care Program, also known as the New Jersey Respite Pilot Project.

Our Department appreciates the opportunity to provide testimony in support of respite services for unpaid caregivers of functionally impaired adults and the frail elderly. I believe that New Jersey's experience in implementing and administering these support services, for families who provide continuing care for disabled and chronically ill family members, will be helpful to Congress, the federal government and other states.

In 1983, New Jersey began to experiment with the concept of providing respite services through a limited demonstration project, which involved offering grants to three community-based agencies to test the effectiveness of services targeted to meeting the special needs of overburdened caregivers. Program evaluation reports indicated that even minimal amounts of in-home service made a significant difference for spouses, parents and children caring for a loved one at home. Encouraged by this, and with the added support of federal demonstration funding, secured through the efforts of Senator Bill Bradley, (P.L. 99-509, as amended by P.L. 100-203), the state launched a statewide program in the Spring of 1988. We were gratified to learn the provisions of Section 4746 of the Omnibus Budget Reconciliation Act of 1990, will allow New Jersey to continue our respite program through September, 1992.

Despite very serious budget constraints in New Jersey, Governor Jim Florio has supported continuation of our Respite Program. While other state programs have experienced funding reductions, the full state appropriation for respite has been maintained for this fiscal year, thanks to the Governor and state legislature. This has enabled us to continue offering respite services at the same level as in previous years.

Our program served approximately 1,900 families during 1990, offering an array of in and out-of home support services for family members who provide constant care for persons with Alzheimer's disease, Arthritis, Cerebral Palsy, Stroke, Multiple Sclerosis, deterioration due to aging and other disabling conditions. We spent nearly \$3,800,000 last year delivering companion, homemaker/home health aide, adult day care, out-of-home respite, caregiver support and education programs. A more detailed description of our program is appended to this testimony.

We do not view respite as a single service, but rather as a strategy to enable families to continue their caregiving role for extended periods of time. This strategy involves offering a menu of services, which families select from, based on their specific needs, as well as those of the impaired family member who requires the care. Using an assessment of the stress and burden level demonstrated by the caregiver as a focal point, our services are designed to provide intermittent, short-term relief and support. For some of our families, that might mean 2 or 3 hours a week of in-home service from a home health aide over a number of months. For others, it might mean placing their loved one in a nursing facility for a 2 week period, so that the family can get away on vacation. For someone who provides care and supervision 24 hours a day, 365 days a year, this can mean the difference between maintaining a child, spouse or parent at home, or feeling compelled to place them permanently in a long term care facility.

New Jersey has also been experimenting with offering some non-traditional services as part of its respite program. For instance, we now offer reimbursement for overnight camp programs for younger physically and developmentally disabled persons, as an alternative to other forms of out-of-home care (nursing home or residential health care facility).

An essential component of any effective Respite program is caregiver support and education. Many persons assume the role of informal caregivers gradually. They may start by doing simple errands or chores for a disabled relative. Over time, especially in the case of the elderly population, functional and cognitive deficits progress to a point where the caregiver begins to provide personal care; bathing, feeding, dressing, assistance with toileting and other tasks that, in the formal caregiving system, are performed *only* by trained personnel. Yet these family caregivers have not had instruction in even the most rudimentary elements of patient care. They risk injury, waste energy and experience increased stress because of inadequate



preparation. We have developed a "Caregiver's Handbook", which explains how to assist with activities of daily living in a simple, straightforward manner. Further, the New Jersey Department of Health has developed an in-home consultation service, which can be accessed by caregivers, to assist in learning to perform essential tasks.

Caregiver support groups, facilitated by professionals, also represent a vital service component in Respite. The opportunity to share concerns, problems and solutions with others in a similar situation can reduce stress and enhance coping mechanisms. Such groups now exist in most areas of our state, and we currently provide funding to initiate these support services, together with grants which are made available through the New Jersey Department of Health, for this purpose.

Recently, the Rutgers University Institute for Health, Health Care Policy and Aging Research, under contract to the New Jersey Department of Human Services, completed a 2 year, independent evaluation of our Respite Program. (Executive Summary attached). Their findings confirm our observations that this program is an effective, low cost strategy which appears to delay or prevent institutionalization while encouraging the natural desire of families to maintain ill or disabled relatives in the home setting.

We impose a "cap" of \$2,400 in expenditures for direct services, per year, per case, for our families. This was done to assure that we could serve a significant number of caregivers. We also have a post-eligibility cost share requirement for our clients. Interestingly, we learned that our clients are more than willing to share in the cost of the respite services they receive. Of the 53 percent of families interviewed during study who are currently *not* required to cost share, 60 percent indicated a willingness to pay towards the cost of care if they were asked to do so.

Our New Jersey caregivers are predominantly female (68 percent), and have provided care for an average of 7 years prior to using our service. Approximately 40 percent of the caregivers are spouses, while another 40 percent are daughters or sons. The average age of caregivers in New Jersey is 64 years old. Eighty percent of these caregivers provide between 12 and 24 hours of care per day for the elderly or disabled person.

Caregivers have responded very favorably to this service, in the Rutgers Study, over 90 percent reported being either "very satisfied", or "satisfied", with the services they received. Forty-three percent reported improvements in their mood and relationship with the person they care for as a result of respite. Ninety-three percent stated that the Respite Program had made a difference in their lives.

We have not found any significant decrease in the amount of care provided by the primary caregiver when formal paid respite services became available. We do note, however, that the Rutgers research indicates that caregiver depression is reduced when they are enabled to leave the house and have "time for themselves."

The average age of care recipients is 78, and 75 percent are females. Eighty-five percent live with the caregiver. Twenty-two percent of our clientele in the study group have Alzheimer's disease, and 42 percent are characterized as having "deterioration due to the aging process."

In conclusion, based on our 3 years of experience, I would like to offer the following recommendations as the Senate Special Committee on Aging explores the role of the federal government in establishing and funding support services for caregivers:

- Respite services should be targeted to caregivers who experience stress and burden in carrying out their roles. In recognition of funding constraints, priority should be afforded to caregivers with the highest objectively measured levels of stress and burden, regardless of the severity of the disability of the care recipient.

- Education and support services are crucial to the success of any strategy to provide respite to caregivers.

- Respite services work and are highly valued by caregivers! Such services should be available nationally and should be government subsidized.

- Cost sharing is a valuable and economically viable option in offering respite. It fosters a partnership between caregivers and government in maintaining disabled and chronically ill persons in community settings.

- Respite services offer a positive method for curbing the governmental expenditures associated with institutional placements.

- Respite programs must offer a variety of services, both in and out-of-home, which enable caregivers to feel comfortable and experience relief, and which are individually tailored to a family's unique situation.

- Respite services should afford the disabled or chronically ill individual positive experiences with formal care systems. Services should be age appropriate and enriching to the individual.

• Government sponsored respite programs should be designed so as to acknowledge, support and maintain the positive contributions of the informal care network, and to provide incentives for families and friends to continue their efforts to avoid or delay the use of institutional placements for the functionally impaired.

National studies show that over 80 percent of all long term care is provided by relatives and friends. We believe that it is reasonable and fair to offer these dedicated, caring people some support and assistance which can reduce their burden and encourage the continuation of their vital services. We wish to compliment the Senate Special Committee on Aging on exploring this most important and timely issue.

Senator BRADLEY. Mr. Ditto, thank you very much. This is very helpful.

Mrs. Sarnoff.

**STATEMENT OF LOLO SARNOFF, PRESIDENT AND FOUNDER,  
ARTS FOR THE AGING, BETHESDA, MD**

Mrs. SARNOFF. My name is Lolo Sarnoff. Thank you, Mr. Chairman for the opportunity to testify today in front of you. I also want to thank you for your concentrated effort to introduce a bill for the respite care for caregivers.

I was a great personal friend of Senator Heinz and I share your great sense of loss.

I am president and founder of the Arts for the Aging, Inc., known as AFTA. AFTA was founded in 1988 as a not-for-profit organization which provides art, music programs, in senior day care centers and in some nursing homes.

Most participants in AFTA programs suffer from dementias. The others are physically or psychologically handicapped. At present AFTA finances 38 programs per month in 13 senior day care centers and has served over 2,800 participants. Most of the programs are pro bono. Only two centers contribute between \$25 and \$50 per month.

AFTA does not pretend to be clinical art therapy, but we provide pure enjoyment in the arts. Until recently, the preferred method of treating medium-advanced demented patients was tying them to a chair, presumably for their safety, giving some calming medication, and letting them sit for hours without stimulation of any kind. TV in many cases is too complicated to understand. For most, reading is no longer possible and self-starting activities usually are out of their reach.

The AFTA program consists of workshops in the visual arts, which includes painting, drawing, sculpture and photography. Music includes sing-alongs and choirs. Folk art provides story telling, quilting and collage. Performing arts includes performances by musicians, dancers and actors. Museum art allows the viewing of works of art in a museum setting. Intergenerational programs involve seniors with school-age children enjoying all of the above jointly.

My interest in demented seniors began when the Art Barn, a small local art gallery of which I was a founding trustee, was invited by the National Institutes of Health to provide art lessons for Alzheimer's patients who were chosen for a special 8 month research program. It soon became apparent that art in every way and form was beneficial to the mood of most patients. The nurses reported that participants were less agitated and aggressive—char-

acteristics of dementias—after partaking in these activities. The NIH study terminated after 8 months, and all the participants returned to their respective homes.

Soon it became known that the Art Barn was giving lessons to Alzheimer's patients. Several senior day care centers applied for this service. After a year the Art Barn concluded that it was not possible for them to continue. Therefore, I decided to create "Arts for the Aging" to meet this special need of frail seniors.

After a short existence of 2½ years, AFTA has accomplished more than I thought possible. I have furnished the statistics for the record.

An active board of 23 trustees including Senator Orrin Hatch; Dr. Nathan Billig, Director, the Department of Gerontology, Georgetown Medical Center; Mrs. Alexander Haig, and Mr. Bill Dunlap, a well known artist, art commentator, and member of WETA's program "Around Town".

250 members, including foundations and corporations.

An office with a salaried part-time director and 2 associates.

16 trained salaried instructors, who teach 36 AFTA programs in 12 senior day care centers.

A published instruction guide for teaching the AFTA method.

Until now AFTA has been funded totally by nongovernment sources; its income derives from contributions of members, foundations, corporations, and benefits.

AFTA's classes are taught by specially trained teachers who are aware of the importance of treating demented people like normal adults, supporting and encouraging them according to their remaining capabilities. These classes and the special care seem to calm participants and increase their contentment. Happiness is a strange word to use in connection with Alzheimer's, although it happens sometimes.

Art can be a great friend, even if no one is Picasso. Producing a creation is pleasurable and stimulating for all senses. Unfortunately, we do not have the opportunity to meet the families of day care participants. However, AFTA has received many enthusiastic letters from day care center personnel.

It is impossible for a caregiver, as everyone has told you here today, to be effective and pleasant 24 hours a day, whilst looking after a progressively deteriorating demented person. Day care centers provide the respite caregivers need so desperately. Therefore, these centers have a double purpose.

It is essential to make senior day care centers available for everyone who seeks this help, even if this service is financially out of reach for some.

AFTA's art classes are a guideline how to organize days for fragile seniors. This guideline seems to be valuable since so many centers are seeking AFTA's services. We have been able to increase centers where we teach from 3 to 13 and art programs from 6 to 38, per month. However, this is only a small drop in a large bucket.

Maybe someday my two great dreams will become a reality. AFTA will develop a prototype of its art classes to be incorporated nationwide in senior day care centers. Second, AFTA will also be able to complete a scientifically controlled study on "The effects of artistic stimulation on the behavior of persons suffering from de-

mentia." I gave a preliminary paper on this subject at the National Gerontological Society Meeting last November in Boston.

As I told you earlier, AFTA has not asked the government for help, however, to make my two dreams come true, we just might.

In conclusion, AFTA's most significant accomplishment is the assistance it lends senior day care centers by providing AFTA's art programs. These pleasurable activities provide demented seniors the possibility to continue to spend part of the day and nights at homes. Second, it gives desperately needed respite to the caregiver, and may postpone the dreaded day of commitment to a nursing home.

Thank you, Mr. Chairman. Thank you, Senator Durenberger.

Senator BRADLEY. Thank you very much, Mrs. Sarnoff. Let me thank all three of you for your testimony.

Ms. Gwyther, let me ask you, how do you see respite care fitting into a national program of long-term care.

Ms. GWYTHYER. I think it's a first step toward long-term care. It's usually the first time that families reach out for any help at all. It may be too late, and they may ask for too little too late, but I think it's a piece. We believe it's the piece between when someone can no longer be left alone and when they need full-time skilled nursing care. So it's not a total answer, but it is a part and it is a first step.

Senator BRADLEY. Mr. Ditto, based on the New Jersey experience, what services do you think are most needed?

Mr. DITTO. Well, I think, actually a variety of services are needed. I can't identify just one. We have heavier utilization of in-home homemaker/home health aide services but that's because many people are not aware of the excellent services provided by social and medical adult day care centers, or are reluctant to use them.

I think from my perspective, it isn't really the type of service so much that's important, but that the services are flexible. As our earlier panelists indicated, there is a need to be able to respond to the unique needs of families.

We really look at respite in New Jersey as a means for replacing what the caregiver normally does. We make an assessment of what the caregiver provides for the person. Are they primarily supervising them so they don't wander off? Are they providing direct personal care? We try to match the services the person receives to the kinds of things that the caregiver would normally do.

Senator BRADLEY. How would you demonstrate that respite is cost-effective?

Mr. DITTO. This is something which we have Rutgers University working on now, in terms of more research for us, because we are very interesting in finding out more about exactly how this works. There's a lot more study to be done in the area of finding out how cost-effective respite is.

It has been our observation that families who receive service under our respite program say to us, almost unilaterally, "We don't feel the need to make an institutional placement at this point. We're going to continue on for the present time and we're going to go as long as we can."

Senator BRADLEY. So your own preliminary assessment is that respite does delay institutionalization?

Mr. DITTO. It definitely delays institutionalization. It gives families options for doing what they naturally want to do, and what they feel really compelled to do, in terms of trying to offer care at home to someone that they love, and that they're concerned about.

Senator BRADLEY. Based upon your comments earlier, I take it that you think that respite caregivers should have some training?

Mr. DITTO. I do, I very definitely do. I think they should be offered training. Now, some family caregivers are very skilled and very knowledgeable about what they're doing. Perhaps the person they care for was hospitalized and then received home health services and training was provided by a visiting nurse, or the caregiver received training when the person was in a rehabilitation center. However, we find a large percentage of the people we're serving are receiving service because of deterioration due to aging and they have not been involved in the formal medical care system, therefore their caregivers have not had any training in how to perform these activities.

Senator BRADLEY. Mr. Ditto and Ms. Gwyther, what about outreach strategies?

Ms. GWYTHYER. I think it's very important because I don't think most people know the word, "respite." They also don't identify themselves as caregivers. They are husbands with sick wives or women with sick mothers. They don't understand what respite means. They all want a lady to come in so that they can take some time off.

Senator BRADLEY. So, your first recommendation would be to change the name of this to the "family caregiver." [Laughter.]

Ms. GWYTHYER. Correct.

Mr. DITTO. It might be a lot easier, we get a lot of calls in our office for the "rez-bite" program.

Senator BRADLEY. From this point forward, the program will be called the "Family Care Giver Program."

Outreach strategies in New Jersey?

Mr. DITTO. Outreach strategies in New Jersey have been very important to us. We've used a number of different methods, including presentations to community groups, flyers, and television spots. It's really important to let people know the service is out there.

Senator BRADLEY. Senator Durenberger.

Senator DURENBERGER. I want to say that to Tom Spadaro that in a little while he's going to need a very special kind of caregiving because his right front tire is flat. [Laughter.]

When Bill responded to the question by the Chairman about what services are needed, I looked down and I said, "Who would have ever thought of that?"

Lolo, it's so nice to see you here. All of us up here, in one way or another, are gifted by the way in which you and Stanley have shared your lives and your talents with all of us. I think we're all much wiser because we just happen to be lucky enough to know you.

Today's is a special gift and it suggests to me something that I know our colleague, Pat Moynihan, has been deeply concerned about. That is, how little we know about the behavioral sciences and I must say, how little attention it seems to be given, even at a time when surgical and inpatient medical facilities are shrinking

in size, and behavioral medical units are opening up. I'm constantly amazed by how little we really know about behavior.

Society expects a certain outcome from a certain set of services. It becomes so difficult to put a value on that because we just don't seem—a broken leg we can recognize. But when we start getting into dementias and mental health, when we get into multiple sclerosis, things like that, it's almost like we're wandering about in a medical field that we need desperately to know more about.

Since one of your dreams is to get this study completed, maybe you can talk to us a little bit about how much more we need to know or what kind of resources we should put into this area.

Mrs. SARNOFF. We still have to know a lot about what influence exposure to art has on the brain. I was fortunate enough to be invited last year to a 2-day study on the brain, which took place here at the National Academy of Science. For 2 days, everybody who had a name in the field of brain, talked, and not a single person mentioned the words art or music, which I thought most extraordinary.

When I was in Boston to give this preliminary report, there were 4,000 participants and about 600 papers which were delivered. Only one of them mentioned, just slightly mentioned, the effect of art on dementia. But strangely enough, the idea that art is important, and although it was a preliminary report, we got a lot of response. I found two very qualified coworkers who want to do this study together with me.

Some of the hospitals in Washington have decided that art is important in dementia, however this is not proven. I want to prove it. It is better to talk about something you know for certain, especially when you are a retired scientist. It's a little difficult to say, "I think so." So, I would prefer to say, "I know." Maybe in 2 years.

Senator DURENBERGER. OK, thank you. Bill, it seems like if we're looking at—I guess it's a different way to ask a question I asked of the other panel—if we're going to look at a capitated payment, and we're going to aim at system flexibility, and we're going to rely on the provider or the manager of care to use the resources correctly, then, at some point, we are going to have to deal with the issue of outcomes. If you don't have an outcome that you can describe or anticipate, then you can't have flexibility and you can't have capitated payments, because you have to prescribe two of this, four of that, six of that, 2 hours a day, you know, 2 days a week, things like that. What are your views on whether or how we could measure outcomes in the whole area that we've been talking about here?

Mr. DITTO. Well, I think one of the ways we can do it, Senator, goes back to what I spoke about earlier—assessing the stress and burden level of caregivers when they begin the respite program, and then studying and looking at what happens to them, and what their experiences are, over time, as a result of participating in the program. Our Rutgers study—which has been going on for 2 years now—has revealed significant changes in both the caregivers mood and relationship with the care recipient for people who have received respite services.

We are now going to have Rutgers undertake a study to look at the people who are currently on the waiting list to determine what

their functional levels are like, and compare those to the family functional levels of the people who are actually receiving a service at this point.

We have a cap of \$2,400—not all of our families use services up to that cap. We have a limit of 14 days a year on out-of-home, in-patient respite care in a medical care facility. We have lots of people who only use that service. That does not come up nearly to \$2,400. With one 2-week break during the year, they're fine for the rest of the year.

Senator BRADLEY. Bill, could you tell us about nontraditional programs and how effective they have been?

Mr. DITTO. Are you referring to the campership service and that sort of thing? Well, we just started experimenting with these, so we'll find out. I will say this, when we look at a 25-year-old man with a spinal cord injury, we really could see putting him in a long-term care facility where the median age was 75, for 2 weeks while his family went away on a trip. It almost seemed punitive. So, when we found out about adult campership programs that provide medical support for people like this, we decided that the service should be as beneficial for the care recipient as it was for the family getting the respite services. So, we're looking at that very carefully. We've only been offering this since last summer and now we're getting a number of requests for camperships.

We're also looking at offering home delivered meals to people with caregivers who work, so they won't be forced to come home everyday, at lunchtime, to prepare a hot meal for a dependent family member. We'd like to be able to offer them a mobile meal service instead. We calculated the price. In New Jersey, it would cost us about \$710. a year to deliver a meal, 5 days a week. This is an alternative to paying for an hour of homemaker/home health aide service to prepare that same meal for the individual. That's what we have been doing up until this point.

Senator BRADLEY. This is the kind of information that is extremely valuable and comes out of the whole respite care demonstration program. I would assume that in Rutgers' evaluation you will see a whole series of these kinds of ideas. Is that correct?

Mr. DITTO. Yes. That's absolutely correct.

Senator BRADLEY. When will that study be complete?

Mr. DITTO. Our first 2-year phase of the study is completed and the executive summary is appended to my testimony. We are authorizing another year's worth of study—we're in the process of doing that now—to answer some additional questions which have come up. So, should the committee have any further questions they wish us to investigate using our program, we will certainly be happy to entertain those. We're very interested in learning more about what kinds of respite services work best for different kinds of clientele, because we are working with a very broad range of people.

Senator BRADLEY. Mrs. Sarnoff, could you tell us what kind of training is needed for the work that you provide?

Mrs. SARNOFF. We have just completed a formal training session for 16 teachers. As a matter of fact, a couple, a Reverend and his wife, came from Ohio, and he is very interested in day care services. You know what, he's very sad it's not a day care center but a

nursing home. He would like to have a day care center instead. He was interested to learn from us what it would take to train people to teach in a day care center. He suggested that a day care center would be more cost effective than a nursing home because the patient could live at home. They wouldn't have to go to a nursing home. Consequently the break with the family, would be delayed and respite would be provided the caregiver.

I feel very strongly that day care centers are needed and it is not terribly difficult to train teachers. AFTA has published an instruction booklet for caregivers and by care centers personnel.

However, one cannot assume that demented people are just like children, as this granddaughter thought. They are not children, they have already lived a long time, and they have had a lot of experiences. They might act like children but they may not feel like children. I think it is very important for this, surely, very charming granddaughter, to understand that her grandmother is not a child, although she may act like one.

AFTA stresses to its teachers the following: A sunny disposition because demented people respond to this. You've got a very positive approach, saying something like, "Everything is just wonderful; we'll do something great today." The negativism of demented people can be overcome, not always and not entirely, there is no 100 percent with them. Third, care must be taken not to do too much for them, or too little. Just enough guidance should be given so they can actually do something for themselves. Sometimes it is only making little circles and doodling like some of us do when we get bored. Others can still produce a work of art.

They adore singing, although not always in tune. AFTA has started a choir at one of the day care centers. I will not say it is the most wonderful choir, but their choir performed at another day care center. It was one of the greatest successes both day care centers ever had—much better than a professional choir because they could enjoy these with each other, even if some sang a little out of tune.

AFTA has had little exhibitions of the art work of various patients. Some participants recognize their own work, some do not, but when told, "I think that this particular work was by you," they might say, "Oh, really, I think it must be, it's the best."

Encouragement is important. Participants return home and are—mostly—there is no hundred percent—less troublesome.

Senator BRADLEY. Well, that makes a very important point on the need to have adult day care in a non-home setting as one of the alternatives. I think that it is very important to keep that as an alternative.

Let me say to all three of you how much I appreciate your help and your expertise in testifying today. We've tried to, in New Jersey, via a demonstration that the country could learn from and to a certain extent I do think that—Bill the program that we've had over 3 years has given us a lot of the information that form the basis of the Family Caregiver Support Act.

I think we just need to, at this time, keep in mind that first panel of witnesses and their personal stories about the amount of love and care that is given, and the expectation that people that are not in the immediate family circumstance would help them



create a nurturing environment for their family member. We also need to recognize the stress that they themselves are under and provide some support for both, in very difficult circumstances.

I think that the message really did come through in this hearing. When you provide support for families who care for their functionally disabled loved-ones, whether the disability is from birth, or from injury, or from illness, or from aging which we all experience daily, the beneficiary is not only the disabled person, but just as importantly it is the family and its members.

I have held other hearings on this subject in New Jersey. I never fail to be deeply moved by the depths of the commitment and resolve that you, as examples of the American family, and you, as examples of the caring professionals, display in an effort to maintain your loved ones in your homes or their communities. It becomes abundantly clear, to all who listen, that this network of support really should be deepened and broadened.

The objective of my "Family Caregiver Support Act" is to do just that. I think as human beings we owe it to each other not only to be kind, but to be caring—the kind of caring that you have all communicated to us today. The cost of family caregiver support programs are small compared to the alternative of institutionalization which is chosen more frequently than necessary when no other programmatic options exist. My legislation will establish a cost effective option.

I want to thank all the witnesses for testifying, and everyone for coming.

[Whereupon, at 4:21 p.m., the committee adjourned, to reconvene at the call of the Chair.]

## APPENDIX

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### ADDITIONAL MATERIAL SUBMITTED FOR THE RECORD

The following case vignettes provide an overview of the types of respite cases currently being served by New Jersey's Respite Care Program. These representative cases were selected from counties throughout the state, and all identifying information has been omitted to assure confidentiality.

#### *"Elderly Caregiver Needs Surgery"*

A 70 year old woman, who provides complete daily care for her 43 year old severely mentally retarded daughter Tina, required surgery which she had been putting off for years. Although she needed the medical treatment, she was afraid of leaving her daughter without care, and was terrified at the idea of having her daughter placed in an institution.

Through the efforts of the county sponsor agency, an aide was placed for 24 hour in-home care, who herself had a child with a developmental disability, and thus lots of personal experience in providing care for this type of client. Tina responded well to this aide, and her mother was able to go forward with the surgery. She expressed a feeling of true relief, knowing that Tina was well cared for while she was hospitalized and that she would be able to recuperate at home without the stress of daily caregiving. A potential institutional placement for Tina was averted by use of the NJ Respite Pilot Program. The mother's health has greatly improved. She reports that she now occasionally uses respite services when she wants to get a little "break" from Tina's care.

#### *"Avoiding A Nursing Home Placement"*

A caregiver in his mid-sixties cares for his 61 year old wife, a retired nurse. She has a history of diabetes and previously suffered a stroke. At the point this case was referred to our program, the client had been in and out of the hospital several times within a short period of time due to congestive heart failure. The caregiver was in serious danger of losing his job, and thus his health insurance, due to his caregiving responsibilities. In addition, this couple were not eligible for any other services because of the income from the husband's employment. When assessed for participation in the Respite Program, they were in a considerable state of stress. An institutional placement was being considered for the wife.

The Respite Program arranged for home health aide service three times per week in order to assist with personal care. Since then, the care-recipient has not been hospitalized, has become ambulatory with the use of a walker, and has been able to leave the house for short periods of time. The caregiver has been able to maintain his employment and thus, the couple's health insurance coverage. Just as importantly, he has peace of mind that his wife is well-cared for in his absence, and is able to continue his care for her with the assistance from this program. It was reported to us that this couple recently visited their daughter in Vermont for the first time since the wife's health problems began. The need for institutional placement was avoided during a critical and vulnerable time for this couple through the use of the Respite Pilot Project.

#### *"The Sandwich Generation"*

The care recipient, an elderly man with diabetes, lives with his daughter and son-in-law. Due to diabetes-related complications, the client is a bi-lateral amputee, blind, hard of hearing, suffers from heart disease and kidney failure. He receives 8 hours of dialysis each day at his home, and requires constant care and supervision.

The care recipient's daughter serves as his primary caregiver. In order to meet expenses, she also works full time from her home, providing family day care for preschoolers. Prior to assuming the care of her father, this woman and her husband had adopted two children. They feel that, up until recently, they were unable to pro-

vide the kind of family life that they intended at the time they adopted the children due to their heavy caregiving responsibilities.

The Respite Program arranged a plan of home health services for four hours each Saturday afternoon. This allows the family time away from home, doing activities that other families often take for granted. They enjoy taking the children to the movies, out shopping, and occasionally out to dinner, knowing that the grandfather is safe and getting care. They have also avoided the difficult and painful alternative of placing a parent in a nursing facility.

Before becoming part of our Respite Program, this family was unable to leave the rare recipient unsupervised, and thus they were unable to spend valuable time together. The respite coordinator reports that this is one of the most gratifying respite cases to date; the couple has achieved a balance of caregiving duties and family life with the support of our respite services.

#### *"Who Will Care For Marilyn?"*

Bette L. is a remarkable mother. For almost sixteen years she has provided daily 24 hour care for her daughter, Marilyn, now age 31. When she was 15 years old, Marilyn developed a brain tumor, and was hospitalized for a series of surgical procedures. During the final operation, she suffered a stroke and lost the ability to speak, walk and perform any self care activities. Mrs. L. brought Marilyn home, and she and her husband took turns caring for their daughter. Two years later Mr. L. died in an automobile accident. Bette, now a widow, made a vow to "keep Marilyn at home with me", despite the urging of relatives and friends that she place her daughter in a long term care facility.

When she learned about the Respite Program through a radio announcement, she reluctantly called the county agency to ask for information. She was depressed and exhausted from caregiving and just wanted to be able to leave the house for a few hours, "you know, to get my hair done, see a movie, visit my sister." During the intake process, she told the respite coordinator, "I'm sure no one would want to be with Marilyn, she can't talk." The coordinator assured Bette that there were caring respite workers available. After a search, a college student was located who could serve as a companion. The coordinator authorized 6 hours of companion service a week. The companion soon learned to communicate with Marilyn by using a "language board" and the two women became fast friends. At first, Bette wouldn't leave the house, but when she saw how the companion interacted with her daughter, she began to feel comfortable. Now she reports that she, and Marilyn, look forward to their weekly "respite day."

#### *"Supporting The Whole Family"*

The care-recipient, an elderly woman with advanced Alzheimer's Disease, came to live with her daughter, son-in-law, and three young grandchildren two years ago, when she could no longer live independently.

The care-recipient's daughter, Mrs. C., serves as her primary caregiver. She reported that during this past fall, she had reached a point where she felt she had lost control of her life, and that of her family, and could no longer continue to care for her mother at the expense of her children. Fortunately, before making the final decision to place her mother in a nursing home, the caregiver learned about the respite program through a social worker.

The respite program coordinator arranged for a social adult day care placement for two four hour sessions each week. This allows Mrs. C. time to do housework, to shop and to be with her children, attending activities with them. The children report that "mommy is nicer." Mrs. C. feels able to keep her mother at home with the family, and has been pleased with the stimulating activities and care her mother gets at the day care center. Respite has benefitted the entire family.

#### *"Multiple Family Crises"*

Mr. T. is an elderly man with a diagnosis of Alzheimer's disease, who has been cared for by his wife ever since his dementia first developed. Mrs. T. rarely gets a full night's sleep, and being in her 70's, has her own health problems. Mr. T. cannot be left alone, wanders, forgets his name and doesn't even recognize his wife.

Mrs. T. was managing, with some support from her son and daughter-in-law, who live in the area, to provide his care. Suddenly she was rushed to the hospital for emergency cardiac by-pass surgery. The respite coordinator was called for emergency placement of Mr. T. in a nursing home. This was arranged, but a daughter from New York subsequently decided to take her father in, and care for him along with her two small children—respite was not required.

Within a day, the son and daughter-in-law again called the respite coordinator from a local hospital to advise that her mother, Mrs. K., had just been admitted

with a diagnosis of Hemolytic anemia, leaving her elderly spouse, Mr. K., who also has Alzheimer's disease, alone. Mrs. K. had to be transferred to a hospital in Philadelphia for care, and the family was in crisis. The respite coordinator immediately effected the placement of Mr. K. in a nursing home for a two week stay, until the family could recover from the crisis and resume caregiving activities. Both Mrs. T. and Mrs. K. recovered, and have returned home and are caring for their husbands—and both are receiving regular, on-going service under the respite program, to help them manage more effectively. Additionally, both women have been attending local Caregiver Support Groups, where they learned more about how to deal with dementia, and experienced the support and concern of others as they continue to cope with their difficult situations.

A quick emergency response from the respite program prevented a series of crises from overwhelming the entire family.

#### *"A Chance For A New Life"*

A 44 year old woman with Multiple Sclerosis, who must use wheelchair and requires assistance with all activities of daily living. She is, however, alert, bright and articulate. She resides with her husband, who works a full time job to support his wife. A daughter and son-in-law help out when they can, but have small children and are limited in what they can do. The husband was overwhelmed, and his income was just a few dollars over the eligibility limit to qualify for any government assistance or home care program. He would work 8-9 hours a day and then return home to bathe and care for his wife, prepare meals and clean. The respite coordinator initially arranged for 7 hours of homemaker service every other Saturday, so he could shop, and do errands. He was very grateful, and indicated that since he would never consider placing his wife in a nursing home, he had just planned to continue caring for her "till he dropped." The small amount of respite service allowed him to "face each day with courage, even if it is a struggle."

In February of 1990, the husband was given a chance for a job promotion, with better pay, which required that the couple relocate out-of-state. The company stated that he would need to agree to move within one month, or they would have to offer the position to another employee.

Despairing, he called the respite coordinator to see what, if anything, could be done for him. She immediately authorized 64 hours of aide service for March (8 hours each Saturday and Sunday for four weeks) to enable the husband to pack and organize the move, while continuing to work during the week. This intensive short-term support enabled him to meet the deadline, accept the position and the couple have just made the big move. His increased salary should allow him to purchase some limited home care service for his wife, since the state he moved to, regrettably, has no respite program in place!

#### *"Young Adult With Special Needs"*

Steven N. is a 27 year old who is Autistic and lives with his parents, both in their mid fifties. Mr. and Mrs. N. must provide constant care and supervision for their son, who is prone to temper tantrums and self-abusive behaviors. Like many individuals with Autism, Steven has difficulty with communication and must be in a structured, protected environment in order to function. He attends a day program several hours a week, while Mrs. N. works a part-time job. Mrs. N., however, must wait until Steven boards the bus, and then must be home when he returns to meet him—he cannot be left alone for even 5 minutes. Mr. N. must work full-time to support the family.

Constant caregiving duties had exhausted these parents. When they learned about the Respite Pilot Project, they inquired about out-of-home care for Steven so that they could take a vacation as a couple. The county respite coordinator recognized that a nursing home would not be a suitable or appropriate placement for this young man. Then she found that a "sleep away" camp program, especially designed for the Autistic, was available for Steven. The respite coordinator contacted the respite administrative staff at the Department of Human Services, and authorization was given to provide this special placement as a respite service for the family.

Steven enjoyed, and benefitted from, his three week stay at the camp, and his parents realized a dream of almost 15 years—the opportunity to take a vacation without their son! The couple report a renewed sense of commitment to keeping Steven at home, knowing that a "break" will be available for them in the future.

## STATEWIDE RESPITE CARE PROGRAM

*Program:* The NJ Statewide Respite Care Program (PL 1987, Chapter 119) has been operational since April 1988. This program provides respite care services for elderly and functionally impaired persons to relieve their unpaid caregivers of the stress arising from the responsibility of providing daily care. A secondary goal of the program is to provide the support necessary to help families avoid making nursing home placement of their loved ones. Services are available for emergency and crisis situations, as well as for routine "respite" for caregivers.

Services provided under the Statewide Respite Care Program (SRCP) include:

- Companions ("adult sitter" type services)
- Homemaker/home health aides (hourly or overnight care by trained paraprofessionals)

- Medical or Social Adult Day Care (out-of-home care in a structured program)

- Temporary Care in licensed medical facilities (admission to a facility for out-of-home care for a brief stay)

The program is administered on a county level by "sponsor" agencies who are responsible for outreach, intake, eligibility determination, care planning, service provision and monitoring. County sponsor agencies include county offices on aging, home care agencies, hospitals, and county social service departments. The actual services are delivered directly by the sponsor agency or purchased by the sponsors from a wide variety of community agencies.

The program serves families with elderly members who have physical and mental impairments resulting from accidents, illness or the aging process, as well as families with members age 18 and above who are physically or developmentally disabled.

There is a cap of \$2,400 per year on services for each case. Applicants for the program must have an income below \$1,221.00 per month and liquid resources of less than \$40,000. Cost-share is assessed for individuals whose income exceeds the federal poverty level. Both the service cap and the cost-share requirements may be waived, with central office approval, on a case-by-case basis.

*Purpose:* The Statewide Respite Care Program has been designed to provide relief and support to the unpaid caregivers of elderly and disabled adults. The goals of the program are to delay, reduce, or prevent the need for institutionalization and to encourage families to continue to provide care, in the community, for their elderly or disabled relatives. The federal government, which provides matching funds under the "NJ Respite Pilot Project", has been interested in learning more about the uses and benefits of respite, and regard our program as a potential model for the development of such programs nationwide. To that end we have also contracted for a two-year research study of this project, as required by the federal grant.

*Cost:* The program is funded at a level of \$4,000,000 for State Fiscal Year 1991 (\$2,000,000 in federal funds, \$2,000,000 Casino Revenue). A total of \$3,700,000 is provided to the 21 county sponsor agencies for program operations and purchase of services. The remainder of the funding is allocated for an on-going program evaluation by an outside contractor (see below) and central office administrative expenses.

The project was originally to have terminated (from the federal perspective) on September 30, 1990. The Omnibus Budget Reconciliation Act of 1990, contains a provision (Section 4746) which extends the demonstration until September 30, 1992 and provides continued federal funding to the Department to operate the program.

*Program Specifics:* Contracts with the county sponsor agencies are managed by the Department's Division of Youth and Family Services Regional Contract system with oversight from the Office of Planning and Special Initiatives at the Division of Medical Assistance and Health Services. On-site monitoring and monthly case and quarterly financial report reviews are also handled by staff of the Office of Planning and Special Initiatives.

An outside evaluation of the program (mandated by the federal government as a condition of funding) is being conducted by the Rutgers University Center for Health, Health Care Policy and Aging Research from June 1989 through June 1991. This contract was established on the basis of a competitive Request for Proposal process conducted by the NJ Department of the Treasury.

*Clients Served:* An estimated 1,900 families received respite services under this program during calendar year 1990. As of December, 1990, there were approximately 500 families on our current waiting list. We expect to serve 2,000 families during calendar year 1991.

For Further Information: William A. B. Ditto, Administrator Office of Planning & Special Initiatives (609) 588-2902.

## EVALUATION OF THE NEW JERSEY RESPITE CARE PILOT PROJECT

## EXECUTIVE SUMMARY

The purpose of New Jersey's state-wide respite care program is to provide relief for unpaid caregivers who are experiencing fatigue and stress from caring for frail elderly or disabled adults. Although the program's services are provided directly to the functionally impaired individual, the purpose is to free the caregivers from their duties and responsibilities for a short period of time. With the relief and support provided by the program, the state anticipates that caregivers will be able to continue in the caregiving role, and will keep the dependent adult at home. A secondary goal is to avoid or delay institutional placement for such dependent adults.

The State of New Jersey first authored a respite care demonstration program in 1983. The following year, the program began providing services in some parts of the state through contracts with three local sponsor agencies. Based on that early experience, and with additional financial assistance from the United States Department of Health and Human Services' Health Care Financing Administration, New Jersey implemented the respite care demonstration on a state-wide basis.

This program (P.L. 1987, Chapter 119), which officially began during April, 1988, is administered through contracts with local "sponsor" agencies in each of the twenty-one counties. The sponsors comprise both public and private agencies. The sponsor agency is the single point of contact for a county's respite program. It may provide any or all of its respite care services directly or through arrangements with other agencies.

Respite provides a wide array of service. The major respite services are summarized in the paragraphs below:

## THE MAJOR RESPITE SERVICES

**Homemaker/home health aide**—includes personal care and household tasks, performed on an hourly or overnight basis by trained paraprofessionals.

**Companion services**—for people who do not require personal care services.

**Medical Adult Day Care**—a structured, medically supervised, out-of-home program in an ambulatory care center for people who are non-residents of that center.

**Social Adult Care**—a structured, out-of-home program provided during the day in a community group setting for the purpose of supporting frail or impaired people in a group setting outside the home.

**Overnight/Brief Stays**—in licensed medical facilities such as nursing homes or residential health care facilities.

## THE EVALUATION OF THE RESPITE CARE PROGRAM

In 1989 the Department of Human Services requested proposals for an external evaluation, in order to fulfill its obligation under the terms of its federal funding, as well as to provide data to guide policy and program development.

Pursuant to the State of New Jersey's competitive bidding procedures, the Institute for Health, Health Care Policy, and Aging Research of Rutgers University was awarded the two-year contract to conduct the evaluation. The evaluation commenced in June of 1989. This report is submitted in fulfillment of that obligation.

The data for the evaluation came mainly from evaluator-conducted surveys and interviews of all county coordinators performed during the winter of 1990; a survey of the vendor agencies which provide respite services under contracts with the county sponsor agencies; and interviews with the caregivers and recipients receiving respite services in April, 1989 who were still receiving services in April, 1990. Also, information derived from each client's initial assessment, conducted when they applied for respite, was analyzed for this evaluation. National Long Term Care Survey data tapes were used for some comparisons. Findings and overall recommendations are summarized in this section.

## COUNTY COORDINATOR SURVEY

*Sponsor Agencies*

Approximately 50 percent of the agencies administering the program are home care agencies. The remainder includes social service organizations, agencies for the aging, and hospitals.

*Coordinators*

Fifty percent turnover occurred among the county coordinators over the study period.

Seventy percent of the coordinators reported that the delivery of respite services usually involves their being in contact with each caregiver at least once a month. Coordinators report spending an average of 8.2 days per month on fiscal record keeping and 6.8 days per month on service record keeping.

One-third of the coordinators expressed negative attitudes concerning the cost share requirement, which establishes a sliding scale by which some clients must pay part of the cost of the respite services. Another 28 percent felt ambivalent about the cost share. Eighty-five percent believed that the requirement had dissuaded applicants from seeking respite. In contrast, 60 percent of respite clients who are not required to pay under the current rules, reported that they would be willing to do so in order to receive respite services.

Eighty percent of the coordinators (interviewed during the winter of 1989-1990) said that the meetings of county coordinators which the Department convenes quarterly, were "very helpful." Thirty-five percent reported having received technical support from the state in addition to the coordinators' meetings; 48 percent reported needing and desiring such support.

Overall, coordinators had very positive attitudes toward the state respite care program, and rated the program very highly.

### *Clients*

Approximately 1,900 different clients were authored to receive respite services during 1989. (Respite utilization data for 1990 is not yet available.)

Client turnover was large—67 percent of the active April, 1989 clients were no longer in the program one year later. Coordinators believe that the caseload has stabilized over the last year.

Caregivers are sometimes facing emergency situations when they apply for respite care. Fifteen percent of the sponsor agencies reported that they receive requests for services during emergencies several times a week to several times a month. Seventy-five percent reported that they encounter such cases several times a year or less. The remainder report receiving requests for services during an emergency about once a month.

### *Outreach*

During the winter of 1989-1990, 65 percent of the sponsor agencies were engaged in client outreach activities. The counties' primary outreach mechanisms consisted of meetings with social service agencies, presentations at community groups and distribution of literature about the respite program. By January 1991, 30 percent of the counties were engaged in such activities. Sponsors attribute this pronounced decrease in recruitment activities primarily to the inability to take on new clients because of budgetary constraints.

### *Waiting Lists*

Between November, 1989 and November, 1990 the total number of people on the waiting list increased from 19 to 348. By November, 1990, 10 counties had waiting lists. In 4 counties, the number of people on the waiting lists comprised 50 percent or more of the number of people on the counties' caseloads. There does not appear to be a relationship between a county's key demographic characteristics and the existence or size of a waiting list.

### *Intake Procedures and Assessment*

Ninety percent of the agencies state that they provide some assistance to clients who are having difficulties filling out the respite application forms.

Need for respite is determined through a standard assessment procedure. Approximately 70 percent of the agencies conduct the assessments in the homes of the respite applicants. In fifty percent of the agencies, respite coordinators or other respite staff conduct the assessment, while in the other agencies assessments are done by vendors or by staff in other divisions within the sponsor's agency. Several coordinators recommended that the state-designed and state-mandated assessment form be streamlined, and redundant questions be eliminated.

The assessment procedure can involve a potential conflict of interest situation when the assessor also provides respite services, as do home care agencies. The "objectivity" of the assessment process, both in terms of determining eligibility and of awarding specific services, is somewhat compromised when the agency performing the assessment is also the agency that would provide the service.

### *Case Management*

For clients not receiving, but requiring, case management, 55 percent of the coordinators said their agency would provide the service themselves, while 15 percent

reported that they would refer the client elsewhere. Twenty-five percent of the coordinators reported that they do not inquire whether or not their clients receive case management services.

Coordinators were asked to describe their involvement in cases where the caregiver decides to arrange long-term institutional placement. The evaluators rated the involvement as to degree. Approximately 20 percent of the coordinators reported behaving in a way the evaluators would categorize as high involvement. Another third described a moderate level of involvement in such situations, while over 45 percent reported a minimal level of involvement.

#### *Services*

Coordinators were asked to describe problems accessing and delivering the various respite care services. The level and nature of the problems differed by service type. Difficulties finding persons to serve as companions were mentioned by 60 percent of all those interviewed. Problems with one or more of the other respite services were mentioned by at least 25 percent of the coordinators. Delays in service delivery were reported by 80 percent of the agencies.

#### *Vendors*

Approximately 80 percent of the county coordinators surveyed reported that they did not use specific standards when selecting the agencies which provide respite services to their clients.

Three-quarters of the sponsor agencies monitor their vendor agencies' performance. The mechanisms relied on consist almost entirely of client feedback or agency visits. The monitoring mechanism differs according to the type of service offered.

#### VENDOR AGENCY SURVEY

There is widespread reliance on vendors by county agencies across the state, and it is apparent that vendors play an essential role in the provision of respite care.

The main activity for the plurality (28 percent) of the vendors responding was the provision of homemaker/home health services. This was followed in frequency by medical day care. Ninety-one percent (N=105) of the vendors identified the primary client population served by them as "the aged."

Sixty percent of the vendors were currently willing and able to accept more respite clients on current terms, while another 24 percent would accept more clients contingent upon some changes (e.g. increased reimbursement rates).

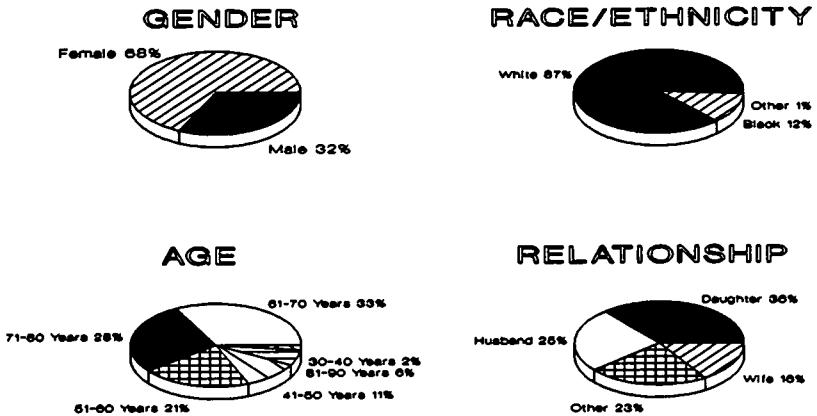
#### CAREGIVER SURVEY

##### *Demographic Characteristics*

Respite caregivers are mostly female (68 percent) and predominantly white (87 percent). The average caregiver age is 64 years old. Approximately 40 percent of caregivers were the children of the care recipients, while another 40 percent were spouses. Other relatives comprised most of the remainder. New Jersey respite caregivers were more likely to be employed and were less healthy than a national random sample of caregivers (based on data tapes from the U.S. Department of Health and Human Services' National Long-term Care Survey). Characteristics of caregivers are presented in Figure 1.



## FIGURE 1 CAREGIVER CHARACTERISTICS



### *Need for Respite*

We found considerable need for respite among the caregivers served by this program. Caregivers had been providing care an average of 7 years prior to the inception of respite. Eighty percent provide care 12-24 hours per day and 86 percent must provide this care during the night.

### *Caregiving Activities*

Over 80 percent of the caregivers help with dressing and bathing, while over 60 percent help with toileting. Caregivers reported that they find the lack of time for themselves, coupled with the related stress, to be the most difficult aspects of the caregiving experience. A substantial number found the physical aspects of caregiving (e.g. lifting) particularly difficult.

### *The Emotional Correlates of Caregiving*

Thirty percent of respite caregivers had Center for Epidemiological Studies Depression (CES-D) scale scores of 16 or above, the threshold score for depression. Higher levels of depression were found among the spouses of care recipients than among other types of caregivers. Sixty percent of the caregivers reported that they felt greatly or moderately burdened by their caregiving responsibilities.

### *Formal and Informal Supports*

Thirty percent of respite clients do not receive any formal social services beyond what they receive from the respite program, while 55 percent receive either one or two such services in addition to respite. Thirty percent received homemaker/home health aide services before respite was initiated. The same percentage received such services in addition to whatever respite services they were receiving after respite was initiated.

Forty-five percent of caregivers reported that no one regularly helps them with caregiving on an unpaid basis. The other 55 percent mostly receive assistance from their relatives. After respite had been initiated, there was a significant increase in the number of times per week that caregivers left their homes to take care of personal matters. This particular measure—how often the caregiver left the home—was, in turn, found to be related to depression levels among the caregivers. Those leaving the home more frequently were less depressed. Interestingly, the amount and the frequency of informal support received by respite caregivers decreased significantly since respite's inception. However the results indicate that the support received prior to the initiation of respite did not enable caregivers to leave their homes very often, compared to support received through the respite program. The decrease in informal support after the onset of respite appeared to occur more often among caregiver-helpers who provided minimal assistance to begin with, which may

help explain why the pre-respite help was not as effective in allowing the caregiver to get out of the house.

#### *Respite Services Received*

Homemaker/home health aide services were received by 75 percent of the caregivers. Fourteen percent reported using day care programs and 17 percent reported overnight stays in nursing homes or residential health care facilities. Although approximately one-quarter of respite clients have utilized more than one respite service, the typical service pattern consisted of one in-home service.

#### *Caregiver Activities*

Approximately 50 percent of the caregivers spent their respite time outside the home doing errands. Close to 25 percent mentioned that they used respite to relax at home or to catch up on housework. Vacationing, visiting and recreation were other frequently mentioned activities.

#### *Reactions to Respite Program*

Caregivers responded very positively to respite. Caregivers rated the program 1.5 (on a 5 point scale where 1 represented "extremely satisfied"). Over 90 percent reported being either "very satisfied" or "satisfied" with the program. We found a significant decrease in caregiver's self-reports of the "burdensomeness" of caregiving. Forty-three percent of caregivers reported improvements in their general mood and in their relationship with the care recipient, as a result of the respite program. Over 90 percent described their experiences with the application and assessment procedures as well as their communications with the sponsor agencies as either "good" or "excellent."

Although half of the caregivers reported experiencing at least one problem with some aspect of the respite care program, problems appeared to consist of one-time issues regarding service delays or difficulties getting along with a particular homemaker/home health aide. Approximately 60 percent of the caregivers who experienced problems said they were satisfied with the way the sponsor agency handled the situation.

#### *Attitudes Regarding the Service Cap and the Cost-Share*

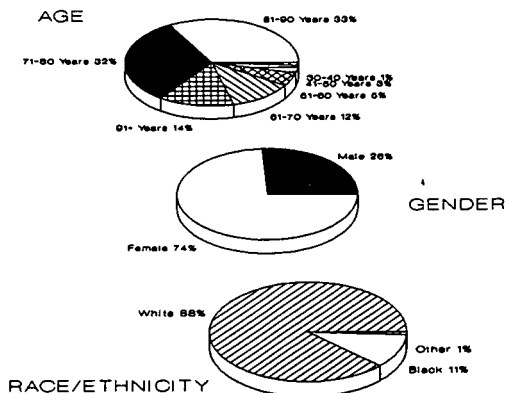
Forty-two percent of persons receiving respite services had accurate knowledge concerning the existence and the specifics of the service cap. Forty-eight percent had no knowledge of the service cap; an additional ten percent knew the cap existed, but could not specify the dollar amount.

Forty-seven percent of respite clients are required to share the cost for their services and fewer than 10 percent of these clients reported that the payment was "more than they could afford." Sixty percent of those who are not required to pay the cost share reported being interested in respite even if they were required to pay something.

#### *Demographic Characteristics of Care Recipients*

Approximately 75 percent of the respite care recipients are female and 88 percent are white. They range in age from 32 to 107, while their average age is 78. Nine percent of the care recipients are age 60 or under. Nearly as many care recipients are married as are widowed (46 percent). The sponsor agencies reported that 5 percent of the care recipients were described as "developmentally disabled." The large majority of the care recipients' medical problems appear age-related. Twenty-two percent were reported to have Alzheimer's disease or related disorders. Characteristics of respite care recipients are presented graphically in Figure 2.

**FIGURE 2  
RECIPIENT CHARACTERISTICS**



### *Comparing Respite Care Recipients to NLTC Sample*

The National Long-term Care (NLTC) Survey was conducted by the U.S. Department of Health and Human Services. It includes a national probability sample of informal caregivers. We compared our results to the national data. Although comparable in age, the two samples differed in their gender distribution. While males comprised approximately one-quarter of the respite sample, only 40 percent of the NLTC sample were males. Our sample of care recipients appears more disabled. Close to 57 percent of the respite care recipients had impairment in 5-6 Activities of Daily Living (ADLs), compared to 42 percent of the national sample. Overall, New Jersey respite clients had impairment in an average of 4.2 ADLs. Over one-half were unable to bathe or to go to the bathroom without assistance. Similarly, 50 percent of the care recipients were completely unable to perform five of the seven Instrumental Activities of Daily Living (IADLs) without assistance.

### *Mental Status of Care Recipients*

Respite care recipients had an average of 6.3 correct responses on the Kahn & Goldfarb mini-mental status test. (A score of 7 or below is typically considered an indicator of a dementing illness.) However, approximately 45 percent performed quite well on the scale, with one incorrect response or no incorrect responses.

### *Interviewer Ratings of Care Recipients*

On the whole, the ratings indicated fairly positive social functioning and emotional condition among respite care recipients. However, these ratings might reflect only the higher functioning recipients, since recipients who could not interact at all with the interviewer were not rated.

## SUMMARY OF RECOMMENDATIONS

### RETAIN RESPITE CARE PROGRAM

The findings offer compelling evidence that the program is meeting its legislated purpose of providing relief and support to uncompensated caregivers of elderly and functionally impaired adults. It is recommended that respite services continue to be supported with public funds, and that the program essentially retain its present structure, which appears to be working quite effectively.

### CONTINUE CURRENT MANAGEMENT PRACTICES

The program appears well-managed centrally by the Department of Human Services. We recommend that this structure continue. We also recommend enhancement of existing management information systems. This system will facilitate the aggregation of program statistics across the state, which will enhance the administrator's

ability to analyze program utilization and cost data, and consequently, to plan and project program trends. In addition, an improved management information system will enable the state administrators to more easily identify and explore unusual patterns or changes in the sponsors' caseload and waiting list data. Until a more sophisticated ADP system is in place, we recommend that each county's monthly contract report be entered into a spread sheet such as Lotus 1-2-3 or Microsoft Excel, so that current state-wide tallies by month, quarter, and year can be rapidly obtained.

We also recommend the continuing data entry of the sponsor agencies' monthly reports. This entry of the sponsors' monthly reports has already been put in place following our previous recommendations. We recommend revising the monthly case reports to make the program data more suitable for data entry and computer analysis. We believe that a more sophisticated management information system will help reduce missing data and decrease data entry errors. All data entered into the data base should be verified. That is, entered twice, and electronically compared for differences.

#### INCREASE DEPARTMENTAL STAFF

We recommend that the Department of Human Services respite staff be increased by hiring an additional staff person who is skilled in management information systems and ADP technology. The clerical staff should also be increased so that there is the equivalent of one full-time person. We are concerned that without this additional staff, the Department will find it difficult to retain adequate control over the twenty sponsor agencies and 150 vendor agencies involved in this complex and geographically diverse program.

#### IMPROVE BUDGET ALLOCATION PROCEDURES

An issue which deserves more careful consideration by policy makers is the allocation formula. The current formula allocates funds to counties according to the relative proportion of elderly and disabled persons residing in each county, but does not also correct for differences among counties in the proportion of low-income residents. Since the program is means tested, it is inappropriate to distribute funds to counties without regard to the proportion of the population in a county who have incomes that would allow them to qualify. Also, the formula should allow mid-year corrections if it appears that particular counties will be unable to utilize all of the funds allocated to them. If some counties could serve more eligible individuals than their appropriation would allow, funds should be reallocated in mid-year, if a mid-year assessment of spending patterns indicates a probable year-end surplus in other counties. This recommendation may require a legislative change.

#### RE-EXAMINE OUTREACH METHODS AND CURRENT ELIGIBILITY LEVELS

A primary consideration in outreach should be to attempt to reach minority caregivers and people who are not already involved in the formal social service system.

Some inconsistencies in initial telephone eligibility screening methods were identified, and recommendations were offered for developing a more consistent and equitable method.

The evaluators also recommend streamlining the assessment form, which is lengthy. We further recommend that the assessment procedure routinely be conducted in the client's home so that the evaluator can obtain a firsthand view of the caregiving situation.

Finally, analysis of patterns of program usage should guide and justify adjustments in eligibility criteria. Eligibility levels should be adjusted if it appears that persons who would benefit from the service are being excluded because their income or assets modestly exceeds the arbitrary current limits on financial resources.

#### ADDRESS PROBLEMS IN SPECIFIC SERVICE AREAS

##### *Companion Service*

For reducing the reliance on homemakers/home health aides when companion services would suffice, the evaluators recommend that the state help counties, or adjacent groups of counties develop companion services, encourage innovative solutions by counties with shortages, and under extreme circumstances allow counties to pay for the travel expenses of paid companions with respite funds.

### *Homemaker/Home Health Aides*

The problems relating to recruiting homemakers/home health aides—especially in the more remote areas, reflect a state-wide and national problem of home care availability which is beyond the power of the respite care program to solve.

### *Medical and Social Day Care*

Although the evaluators have learned that some additional counties have begun to contract with day care programs in the last year, such services are not readily available everywhere. Where day care programs are unavailable the evaluators recommend assisting the local sponsor to develop them when feasible. The state has indicated its willingness to do this.

### *Contract Issues*

Where the contracting procedures of sponsor agencies are so cumbersome as to impair the capacity to attract and hold the most appropriate vendors, it is recommended that coordinators work within their own agencies to simplify the process. The complexity of an agency's contracting procedures should be considered by the state as one of the factors in determining the suitability of an agency to serve as sponsor.

### *Delays*

Delays in the provision of respite services are usually due to the unavailability of homemaker/home health aides at the current reimbursement level for this service. The evaluators recommend that the state authorize, in emergencies and on a *case-by-case* basis, the purchase of homemaker/home health aide services at higher than authorized rates. Such a policy could be controlled by specifying the maximum number of hours that are authorized at the higher rate.

## DEVELOP SPECIFIC PROGRAM AREAS

### *Special Requests*

The data seem to indicate that the state administrators of the respite program exhibit considerable flexibility regarding special service requests. However, county coordinators often do not know the range of circumstances in which special requests can be made. We recommend that they be provided with examples of requests that have been approved or denied.

### *Transportation Service*

For clients with no other options, we recommend that the state should continue its current practice of allowing transportation as a respite service on a *case-by-case* basis. Coordinators should be reminded periodically that this service is available under special circumstances.

### *Support Services for Caregivers*

We recommend that each county attempt to link caregivers with existing support groups. When such support groups are unavailable, we recommend that the sponsor agency initiate such a group.

### *Respite for Working Caregivers*

Although the policy had been to bar respite services during hours when the caregiver is at work, this policy was found to be problematic and has recently been changed. Under certain circumstances, respite services during the working hours of a caregiver may be warranted. In these truly exceptional circumstances, we recommend that deviations from policy be authorized. Coordinators should be reminded periodically of the current policy.

## PROVIDE INCREASED RESPITE FOR FEMALE CAREGIVERS

We recommend that the federal statutory requirement be changed by adding the following language to Section 9414 (c)(1)(B)(i) of the Omnibus Budget Reconciliation Act of 1986: "or whose joint income, including the income of the spouse, does not exceed twice this amount, or . . .".

## PROVIDE COUNTIES WITH TECHNICAL ASSISTANCE REGARDING RECORD KEEPING AND BILLING

While coordinators tended to be laudatory concerning the state administrator's flexibility and familiarity with the program's needs, their few critical comments pointed to the need for enhancements in the area of management information systems. Coordinators reported spending at least eight days per month on record keep-

ing. We recommend that the state devise a simple, uniform computer program that could be used state-wide to input service and fiscal data, and that coordinators receive training in the implementation of the new system.

#### PROVIDE CASE MANAGEMENT ORIENTATION TO ALL COUNTY COORDINATORS

Coordinators should know who is filling the role of case manager for every one of their cases. When a case manager is involved, the case manager should be informed, with permission from the caregiver, that respite services are being provided. If it is determined that there is no case manager, and such services appear to be needed, it is recommended that the coordinator refer the family to an appropriate source for such services. If none can be found, the coordinator should discuss the case with the state respite care staff to find a solution.

#### DEFINE COORDINATORS' ROLE IN NURSING HOME PLACEMENT

Since many respite care recipients will eventually go to nursing homes, we recommend that a procedure be developed so that appropriate help can reach families when such placement is needed. We recommend that the state periodically educate coordinators concerning existing resources, providing guides and information and referral numbers, and that it require assurances that the coordinators are providing such information to their clients when the need arises.

#### EXPAND THE INFORMATION AND REFERRAL SERVICES OFFERED BY RESPITE

When clients need help in acquiring services or applying for benefits beyond what is available through the respite program, the respite coordinators should provide their clients with the phone number of the county-wide information and referral system and should remain informed of the status and quality of this system. When the county-wide system is inadequate, the respite coordinators should assume a greater responsibility for knowing about the local human services system, and if no other entity is adequately providing this kind of information and referral service, the respite coordinator should refer clients directly to other agencies as needed. We also recommend that the state consider the possibility of developing a state-wide caregiver handbook.

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### PREPARED STATEMENT OF BETH A. RABINOVICH, PH.D.

#### 1. SPECIFIC AIMS

In the past ten years, there has been a proliferation of adult day care centers. There are currently 73 licensed adult day care centers in the state of Maryland. They provide an array of health and social services. These services are based on one or more of the following objectives: (1) To maintain independence, (2) to rehabilitate the attendee, (3) to delay or prevent institutionalization, and (4) to provide respite for family caregivers. Two years ago, Arts for the Aging, Inc. (AFTA), was founded as an innovative nonprofit arts and educational organization concerned with improving the quality of life for senior citizens, especially those suffering from dementing disorders. AFTA's objective is to provide creative experiences for participants of senior day care centers. In this program, professional artists, dancers, and musicians are trained to provide activities for participants of adult day care centers on a routine basis. Qualitative reports show that the majority of the participants in activities sponsored by AFTA were positively affected by participating in the classes (Sarnoff, Meloney, & Billig, 1990). Despite the increase in the number of adult day care centers and the provision of structured activities, there is a dearth of empirical studies examining the impact of participation in these activities.

The aim of this study is to examine the impact of participation in a structured art activity on the behavior of day care attendees suffering from dementing disorders. The art activities will be provided by an AFTA teacher. Naturalistic observations of subjects' behavior will be recorded during AFTA activity times. Behavior during a period when there are no activities will also be recorded. Therefore, we will be able to compare the subjects' behavior during activity and nonactivity periods of the day. Empirical data of this type could provide policy makers and program developers with information beneficial in planning activities that are appropriately stimulating for day care attendees suffering from dementing disorders.

## 2. BACKGROUND AND SIGNIFICANCE

There is much speculation as to whether elderly persons suffering from dementing disorders should be exposed to structured recreational activities. Some argue that participation in structured activities provides little benefit, especially to those who are in the later stages of dementia, while others argue that exposure to activities, at the very least, provides stimulation that enables demented patients to maintain their abilities for as long as possible (Jenkins, Felce, Lunt, & Powell, 1977). Although these are important issues, there is a dearth of research examining the effectiveness of participation in structured recreational activities. The few extant studies are preliminary in nature, and they are primarily studies carried out in nursing homes.

Two studies that evaluated the impact of programs on special units of nursing homes draw somewhat different conclusions. Loew and Silverstone (1971) found that nursing home residents who were exposed to physical, social, and psychological stimulation, in comparison to a control group, improved on a cognitive measure, but the difference was not statistically significant. Qualitative reports showed that the subjects in the experimental group had more energy in general and seemed more agitated. Cleary, Clamon, Price, and Shullaw (1988) evaluated the effects of a reduced stimulation unit that provided a caring environment, and appropriate activities for Alzheimer's residents. Residents of the reduced stimulation unit showed a significant improvement on a behavioral scale, and qualitative reports showed that agitation seemed to decrease. Subjects' weights, which before entering the special unit had been below normal, improved. While the level of agitation increased in one study, and decreased in the other, these results are based on qualitative data.

In a microanalytic study examining reactions to music, touch, and object presentation in two patients in the final stage of dementia, Norberg, Melin, and Asplund (1986) observed that both patients reacted differently to music than to touch or object presentation. They concluded that it is possible to make contact with patients in the late stages of dementia, and their reactions can be evaluated.

Two studies examined behavior during activity and nonactivity periods. The first study compared the rate of purposeful activity of 42 residents in a hospital geriatric ward for regressed and disabled persons during periods of programmed activity (e.g., bingo) and no activity. Results showed that only 3 were engaged in some purposeful activity during periods when there were no programmed activities, but during programmed activity periods, 13 residents were engaged in purposeful activity. The number dropped to three when the activity was terminated. In the second (Rabinovich & Cohen-Mansfield, 1990), 13 nursing home residents living in an Alzheimer's unit were observed while they were participating in activities involving a ball, or physical exercise. All the subjects had severe cognitive impairment. The subjects' agitated behavior (e.g., repetitious mannerisms, strange movements, verbally agitated behavior, etc.) was observed before, during, and after activity time. The weighted composite mean for the activity segment was slightly lower than the means for the pre- or post-activity segments. Although the differences between the means were not statistically different, the results of this study demonstrate that it is possible to observe and record behavior during activity times, and that participation in structured recreational activities may impact on the behavior of nursing home residents even in the later stages of dementia.

The proposed study extends the work in this area in several fundamental ways: (1) By examining behavior during the AFTA activities, and during a period when there are no such activities, it will be possible to examine the impact of participation in activities on the behavior of community-dwelling elderly suffering from dementing disorders enrolled in an adult day care program; (2) by examining the behavior of the AFTA teacher, it will also be possible to examine the relationship between the behavior of the teacher and day care attendee; and (3) by examining the family caregivers' rating of subjects' behavior on the evening after each observation it will be possible to measure the effect of participation in a structured art activity on the subjects' mood.

## 3. EXPERIMENTAL DESIGN AND METHODS

The proposed study will address the following questions:

1. What is the impact of participation in a structured art activity and day care attendee's behavior?
2. What is the relationship between level of participation in a structured activity and level of cognitive functioning?
3. Is there a relationship between the subjects' behaviors and the behaviors of the AFTA teachers?

#### 4. Does participation in a structured activity influence level of depression and mood?

##### *Subjects*

Subjects will be 50 elderly persons, 65 years and older, suffering from dementing disorders who attend day care centers that are affiliated with Arts for the Aging, Inc. The Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975) will be administered to day care attendees who typically participate in AFTA activities. Those who score below 24 points on the MMSE (except those who suffer from profound hearing or vision loss) will be recruited for the study. Informed consent will be obtained from participants who are able to understand the nature of the study. For those who are not, it will be obtained from their closest relative.

The research assistant will obtain demographic data, such as age, sex, marital status, length of attendance in day care, and reason for attending day care from the day care centers' records.

##### *Procedure*

The behavior of each subject will be observed on two occasions. The first observation will be during an AFTA sponsored art activity. The second observation will be on another day at approximately the same time as the first observation, but during a time when there are no scheduled activities. The research assistant will administer the Geriatric Depression Scale after each observation. On the evening after each observation, family caregivers will be contacted by telephone and asked several questions about the subject's mood and behavior that evening.

##### *Assessments*

*Demographic Variables.* A research assistant will obtain the following information from the subjects' files: Age, sex, marital status, length of attendance in day care, reason for day care placement, and diagnosis of dementing disorder. Whenever possible, medical diagnoses will be recorded from the files.

*Assessment of Cognitive Functioning.* The Mini-Mental State Exam will be administered to each participant (MMSE; Folstein et al., 1975). The MMSE is a brief screening test that has become a standard clinical research tool over the past decade. Based on our experience, administration of this tool will take from ten to twenty minutes per subject. Scoring is accomplished on a scale of 0-30; a score of less than 24 indicates cognitive impairment. Data pertaining to the reliability, validity, sensitivity, and specificity of the MMSE have been reported in elderly subjects (Cockrell & Folstein, 1988).

Although the MMSE is widely used in the assessment of cognitive functioning, it alone is not sufficient because it is not appropriate for all persons. It yields little information from those who suffer from severe dementia. Therefore, a day care provider will be asked to complete the Brief Cognitive Rating Scale (BCRS; Reisberg et al., 1983) for each subject.

Four axes of the BCRS (concentration, recent memory, past memory, and orientation) will be assessed for each participant; then, the 4 values will be averaged for each participant, yielding a single BCRS score. Pearson correlations of the BCRS axes with independent psychometric and mental status questionnaire assessments were statistically significant and ranged from .51 to .84; interrelationships among the BCRS axes were between .83 and .94 (Reisberg, et al., 1985).

*Assessment of Level of Depression.* The Geriatric Depression Scale (GDS; Brink et al., 1982) will be administered after each observation. The GDS consists of 30 yes/no questions; a score of 0-5 is within the normal range, 6-10 signified mild depression, and a score about 10 indicates marked depression. Reliability and discriminant validity have been reported (Yesavage et al., 1983a; 1983b).

*Assessment of Activities of Daily Living.* Performance of activities of daily living (ADL) will be assessed by the family caregiver through six items—toileting, feeding, dressing, grooming, bathing, and ambulation—from the Physical Self-Maintenance Scale (PSMS; Lawton & Brody, 1969). They will be asked to complete the questionnaire and return it via mail.

*Assessment of Behavior During Observations.* Each subject will be observed twice on two separate occasions. The first observation will take place during an AFTA activity. The second will occur within the next few days at approximately the same time when there is no planned activity. During the observations the research assistant will stand near the subject, and as unobtrusively as possible record the subject's behavior during the activity. The observation system is designed to sample the behavior of the subject and the AFTA teacher. The time-sampling cycle is composed of a 10-second observing period followed immediately by a 20-second recording period. A stopwatch is used to indicate the continuing cycles of 10-seconds-observe, 20-sec-



onds-record, 10-seconds-observe, 20-seconds-record, etc. On occasion, a subject may fall asleep during an activity or leave the room. There will be a column on the coding sheet where these behaviors can be recorded. The following behaviors are on the coding sheet:

*Day Care Attendee Behaviors:*

Vocalize to Teacher (or Day Care Provider) (positive or neutral)  
 Smile/Laugh  
 Attend Object  
 Manipulate Object Appropriately  
 Proffer/Show Object Appropriately  
 Agitated Behavior (e. g., scream, pace, repetitious mannerisms, etc.)  
 Out of Room  
 Sleep

*Teacher or Day Care Provider Behaviors:*

Vocalize to Subject  
 Smile/Laugh to Subject  
 Encourage Attention to Object  
 Encourage Manipulation of Object  
 Praise  
 Touch  
 Restrict-Prohibit Manipulation of Object

*Assessment of Behavior and Mood by Family Caregivers.* Subject's mood and behavior will be assessed by their family caregiver in the evening after each observation. Family caregivers will be contacted by telephone and administered a short questionnaire. They will be asked to rate their relatives' mood and general behavior on a five-point scale.

*Data Management and Analyses*

The data will be double-coded and entered onto an IBM PC independently by the research assistant and research secretary. To eliminate data entry errors, the two data sets will be compared using a computer program. The data analyses will be performed using SAS statistical software on the personal computer.

Before data collection commences, the principle investigator and research assistant will simultaneously observe eight subjects, and reliability will be calculated. To describe the sample, descriptive statistics such as frequency distributions will be performed for sex, diagnosis of dementing disorder and marital status. Means will be calculated for age, and length of attendance in day care.

Data analysis follows directly from the research questions. A multivariate repeated measures analysis of variance will be performed to address question 1. The within-subjects factor will be time with two levels: in art activity vs. not in art activity. The attendees' behaviors will be the dependent measures. To address question 2, a multivariate analysis of variance will be performed on the data from the observations of AFTA activities. The between-subjects factor will be cognitive functioning. The dependent measures will be the day care attendees' behaviors. To examine the relationship between the subjects' behaviors and the AFTA teachers' behaviors, correlations will be performed. Repeated measures analyses of variance will be performed to examine the relationship between participation in a structured activity, mood and level of depression.

4. TIMETABLE AND BUDGET

*A. Timetable*

The proposed project is for an eighteen month period. In the first four months, a research assistant will be hired and trained to record the time-sampled observations. The research assistant will obtain informed consent and abstract information from the day care attendees files. Data entry will begin during this period.

During months 5 through 14, the principal investigator will observe the subjects and record their behavior via the method described above. She will also administer the Geriatric Depression Scale and the Telephone Interview. During this period, the research assistant and research secretary will perform data entry.

Data checking and analyses will be performed during months 15 and 16. A journal article and a report of the findings of the study will be completed during the final two months of the study.

*B. Budget*

Personnel:	Time	Amount
Principal Investigator: Beth A. Rabinovich, Ph.D.....	.70	\$47,250
Research Assistant (Research Institute).....	.20	7,500
Research Secretary (Research Institute).....	.10	3,750
AFTA Executive Director.....		1,200
AFTA Program Director.....		1,200
AFTA Artists.....		7,000
AFTA Secretary.....		1,200
Benefits: (22%).....		15,202
Consultants.....		8,250
Supplies for the Research Institute.....		1,050
Supplies for AFTA.....		3,000
Photocopying.....		450
Mail.....		150
Equipment.....		150
Telephone.....		450
Local travel for the observer.....		1,040
AFTA local travel.....		250
Subtotal.....		99,092
Overhead: (for the Research Institute) 15%.....		14,864
Total Budget.....		\$113,956

## PERSONNEL

**Principal Investigator:** Beth A. Rabinovich, Ph.D. Dr. Rabinovich, who has over ten years of experience conducting observational research, will be responsible for the overall direction of the proposed project. She was a recipient of an Alzheimer's Association 1989 Pilot Research Grant, "The Relationship Between Agitated Behavior and Structured Activities in Nursing Home Residents Suffering from Dementia: An Observational Study." This study involved videotaping residents during activities, and coding their agitated behavior from the videotapes. She has extensive experience in all aspects of observational research from the National Institute of Child Health and Human Development, Baylor College of Medicine, and the Research Institute of the Hebrew Home of Greater Washington. She will be involved in all aspects of the research from data collection, data analysis, and report writing. She will spend 70 percent of her time on this project for the 18-month project period.

**Research Assistant:** To be named by the Research Institute. The research assistant will be responsible for obtaining informed consent and obtaining reliability with the principal investigator. She will also be responsible for data entry. She will spend 20 percent of her time on the project for the 18-month project period.

**Research Secretary:** To be named by the Research Institute. The research secretary will be responsible for performing general office duties, and data entry. She will spend 10 percent of her time on this project for the 18-month project period.

**AFTA Artists:** To be named by AFTA. Professional artists who have received special training to teach art activities to elderly suffering from dementing disorders will conduct the activities for the study. They are paid at the rate of \$50 per activity.

**AFTA Personnel:** The Executive Director, Program Director, and Secretary will each receive a fee of \$1,200 for performing supervisory duties, scheduling AFTA artists, or general office duties.

*Consultants*

**Nathan Billig, M.D.** Dr. Billig is on staff at Georgetown University Medical Center where he is a professor and Director of the Geriatric Psychiatry Program, and Director of the Center on Aging. He is the author of the book, *To Be Old and Sad: Understanding Depression in the Elderly*. He is currently the principal investigator of a study examining the effects of elective surgery on community-dwelling elderly persons (funded by NIH). Dr. Billig is on the Board of Trustees of Arts for the Aging, Inc. He will consult for 8.5 days at \$350 per day.

**Jiska Cohen-Mansfield, Ph.D.** Dr. Jiska Cohen-Mansfield is a professor of psychiatry and Director of Research, Center on Aging, Georgetown University School of Medicine. She is nationally known for studies of the agitated behavior of nursing

home residents. She has served as principal investigator of a large study examining the agitated behavior of nursing home residents funded by the National Institute of Mental Health, and she is currently the principal investigator of a longitudinal study examining agitated behavior in community-dwelling elderly funded by the National Institute on Aging (NIH). She will consult on the study design and data analyses. She will consult for 15 days at \$350 per day.

L.C. Sarnoff. Mrs. Sarnoff is the founder and President of Arts for the Aging, Inc. (AFTA). AFTA is a nonprofit arts and educational organization concerned with improving the quality of life of mature citizens. AFTA's primary objective is to improve their quality of life by providing arts programs such as dance, drama, folk arts, music, painting, print making, poetry, sculpture, museum visits, and story-telling. AFTA also trains artists to work with elderly who suffer from dementing disorders. AFTA has received grants from major foundations including the Mobil Foundation. Mrs. Sarnoff will serve as an unpaid consultant.

#### *Other Expenses*

Supplies for the Research Institute: Included in supplies are paper, pencils, computer related items (e.g., floppy diskettes, paper, etc.), and stationery.

AFTA supplies: Included in AFTA supplies are art materials for the structured activities and general office supplies such as paper, pencils, computer related items and stationery.

Photocopying: Funds are requested to cover the costs for photocopying coding sheets and other forms.

Mail: Funds are requested to cover the costs of sending materials to subjects.

Equipment: Funds are requested to purchase special clip boards and stopwatches for recording the time-sampled behavioral observations.

Telephone: Funds are requested to cover costs for telephoning the adult day care centers and interviewing the subjects' family caregivers.

Local travel for observer: Funds are requested to cover travel to the adult day care centers.

Local travel for AFTA staff: Funds are requested to cover local travel for AFTA staff to travel to day care centers to supervise their program.

Overhead: A 15 percent overhead is requested to partially cover computer maintenance, rent, etc.

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#### PREPARED STATEMENT OF MEREDITH E. WAGENBLAST

I regret tremendously that I am unable to attend the hearing on the N.J. Respite Care Program. I am grateful, however, to have the opportunity to submit this written testimony on behalf of the project. For my mother, Beatrice Newbon, a victim of Alzheimer's Disease, and for myself and my family, the respite care program has been a tremendous blessing. Without it, I doubt very much that we would have been able to care for my mother in our home for as long as we have.

Approximately 4 1/2 years ago, my mother, who is now 80 years old, was diagnosed as having Alzheimer's Disease. My father had just recently died, and my mother was living alone in her home in a retirement village about 20 minutes from our home in Toms River, NJ. For a year and a half, I visited my mother every day to assist her in a variety of ways. Eventually, living alone became not only too difficult for her but also too dangerous for her safety and well-being. My husband, Dennis, and I decided the time had come for her to live with us. That was about 3 years ago.

At the time, I was cautioned by doctors, my minister, friends, and members of an Alzheimer's Caregivers Support Group that caring for my mother as the disease progressed might not only be difficult but also very stressful for us and for our three young children. At the time I felt very confident and capable of handling the situation. After all, this was my mother, and I could not imagine placing her in a nursing home or even having homemakers come to help me care for her. We went ahead with our plan to add on a first floor addition for her, and at first, things progressed just as I had hoped they would.

Gradually, however, our lives as a family began to suffer. We could not leave my mother alone for more than brief periods. When my children had friends over, she became very agitated and nervous. There were no more family outings, and we could never go away for a weekend. I began to realize that I would have to seek help.

I had met Barbara Wolfson from the Ocean County Board of Social Services at a caregivers' meeting I had once attended. She had offered assistance to me whenever

I felt it was necessary, and so I contacted her. It was through Barbara that I was introduced to the respite care program, and my mother was enrolled. Although there have been other avenues I have pursued in caring for my mother, respite care is the one that by far has meant the most to us as a family. It has enabled us to better bear the strain of watching the deterioration of a loved one and caring for her.

Alzheimer's is a very unpredictable disease, and my mother has suffered through many stages of it. At first, she lost very specific abilities which involved numbers, facts, specialized skills such as typing and writing. Then she lost more basic abilities such as dressing and undressing, preparing the simplest of meals, finding her way around the neighborhood. It was during these stages that she came to live with us. Helping then was an easy and happy task for me, and I was glad that she could be with us.

During the past year, though, the disease has caused changes that are harder for all of us to accept. Walking and sitting have become dangerous ordeals for her, and she has become terribly stooped over, which causes her to fall quite often. Eating, which was always a pleasure for her, has become quite difficult, and she has lost a considerable amount of weight. Even things she used to love like seeing the ocean or watching her favorite TV shows hold little interest for her now. Once a wonderful teacher and excellent speaker, she now has difficulty putting thoughts into words and words into sentences.

The hardest part for me is that her personality has changed so much. I would hardly recognize her as my mother. I never know which "person" I am dealing with. At times she is kind, loving, and fun, just like she always was. But very suddenly she may become very hostile and antagonistic or she may become very depressed and start to cry. She has terrible nightmares that keep her up much of the night and leave her exhausted during the day. She confuses fantasy and reality. It is a roller coaster of emotions for her and for all of us. She is like a lost soul, who doesn't know who she is or who we are much of the time. She gets lost in her own room.

But for others, caring for a loved one with Alzheimer's is far worse. I see so many older couples in which one is ill and the other must bear all the burdens and responsibilities alone. I have my family to provide help and support for me. But for the elderly spouse, there often is no one else nearby to help. So many do not qualify for Medicaid, yet they cannot afford to have homemakers or to send their loved one to daycare. Often the physical and emotional strain become too much, and the caregiver often becomes ill and dies before the Alzheimer's victim. It is in situations such as this that the respite care program may literally mean the difference between life and death. Having someone come in to provide a break for the caregiver can make all the difference in the world. The fact that the program is so flexible and adaptable to the needs of those involved is one of its greatest benefits.

Our family utilizes respite care by having a homemaker come for 6 hours every other Saturday. I often say these are the best times of the month for us. During the week, we pay for my mother to attend an Alzheimer's day care program provided by Visiting Homemaker Service of Ocean County. We also at specific times have a homemaker come for an hour to sit with my mother when necessary. While these programs are great, they are very expensive and do not help us as a family to do things, because they occur while the children are at school. We could not, on a regular basis, afford to have a homemaker come for 6 hours on Saturdays—the time when our family needs it the most. And that is why respite care is such a wonderful gift to us. It enables us to attend together the children's sports games, to go to the park or the beach, or to visit friends. It completely frees us for a large portion of the day, and it is great!

I honestly do not know how much longer we will be able to care for my mother at home. Placing her in a nursing home will be one of the most difficult and heart-breaking decisions of my life. One thing that will comfort me, however, is that thanks to respite care, we have been able to keep her with us far longer than we could have otherwise. Thanks to respite care, the quality of my mother's life and ours has been much better. For this, we will always be grateful to Senator Bradley and to all those who have helped to make this program possible. It is our prayer that respite care will not only be continued in New Jersey, but that it will also be expanded, so that the thousands of families across our country who are in such great need of this kind of relief may benefit as we have.

Thank you again for the opportunity to submit this testimony.

ASSOCIATION FOR RETARDED CITIZENS OF THE UNITED STATES,  
 WASHINGTON, DC 20005,  
 May 7, 1991.

Hon. DAVID PRYOR,  
 Chairman, Senate Special Committee on Aging,  
 G-31 Dirksen Senate Office Building,  
 Washington, DC 20510.

DEAR SENATOR PRYOR: On behalf of the Association for Retarded Citizens of the United States, I want to thank you and the Special Committee on Aging for holding a hearing on April 23 on the need for respite care for families of people who are disabled or elderly.

The ARC has long held that an individual's need for facility-based care in a nursing home or Intermediate Care Facility for the Mentally Retarded is less dependent on the level of severity of the person's disability than on the availability of appropriate support services for the individual and the family. We are told time and again by our members and others that the initial reason for out-of-home placement of a child or other family member with a disability was the family's inability to obtain services to help sustain the individual in the family home or community.

We urge the members of the committee to keep in mind that respite care is only one component, albeit a very important one, of a comprehensive service system that would truly address individual needs. While respite services (or family caregiver support services) do not by any means address all of the needs of individuals who wish to remain in their own homes, the availability of such services would be very critical to many families.

The ARC believes that certain principles should underpin any respite systems or services that are developed. Services should address the needs of people without regard to age or cause of disability. Systems should be flexible and responsive to individual and family needs, fitting the service to the circumstances rather than fitting the person or family to the "slot" or opening in the service delivery system. In addition, the system must place a high priority on individual choice, preferences, and values and place the individual and family in a central position regarding decisions about service design, location, frequency, and duration.

The availability of respite care is a high priority for our membership. We stand ready to work with you and the committee to address these important concerns. Again, we appreciate the committee's attention to respite care issues and look forward to working with you this year. If you have any questions or want any further information, please contact Marty Ford in the ARC Governmental Affairs Office (202-785-3388).

Sincerely,

RALPH J. MOORE, JR.,  
 Chairperson, Governmental Affairs Committee.

IONA HOUSE SENIOR SERVICES,  
 WASHINGTON, DC 20016,  
 February 14, 1991.

Mrs. LOLO SARNOFF,  
 President, Arts For The Aging, Inc.,  
 410 8th St., NW, Suite 405,  
 Washington, DC 20004.

DEAR LOLO: This marks the beginning of the fourth year that you have touched the lives of our frail older participants, first through the Art Barn, and now with your own organization, Arts For The Aging.

For our patient's with Alzheimer's, memory loss, and other dementias, the creative programs you've provided have dramatically enhanced the lives of these forgotten individuals. Our staff has been impressed with the degree of sensitivity displayed by the AFTA artists, and with the positive response they have elicited from the participants. It is difficult to measure the intangible qualities which these creative experiences enhance: pleasure, pride, happiness, reminiscing, laughter, accomplishment. Easier to measure, yet of no greater importance than those qualities, is the significant reduction in participants' anxiety and agitation both during and following AFTA classes. The AFTA artists engage the participants in purposeful activity, while at the same time tap their own rich (despite notable losses in intellectual functioning) emotional inner life.

As our world population continues to age, we may begin to know more about the effects of memory loss and other dementias, and the ways to continue to promote quality of life for the millions of individuals who are, or will be, affected. An organization like Arts For The Aging plays an important role in this learning process. AFTA's mission puts you on the cutting edge of community programming with these impaired persons, and the needs of these individuals will only increase.

Thank you for your continued dedication to this important cause. We hope that we can continue to count on AFTA's regular involvement in enhancing the lives of our participants, half of whom have Alzheimer's or other dementias. Wishing you every continued success.

Sincerely,

MELISSA BROWN MANSUETI,  
*Day Health Center Director.*

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